Montana Comprehensive Cancer Control Plan, 2006-2011

Montana Cancer Control Coalition: Working Together.

Cover Letter:

May 2006

We are pleased to present you with a copy of this newly released Montana Comprehensive Cancer Control Plan 2005-2011. If you have received more than one copy, please pass the extra to a friend or colleague.

Montana's Comprehensive Cancer Control Plan is a living document designed to guide a unified and collaborative effort covering the five-year period between 2006 and 2011. It offers a framework for statewide cancer prevention and control, utilizes evidence-based strategies and sets priorities for public and private cancer-control activities. The intent is to implement the plan by engaging individuals and organizations to work together to control cancer. Cancer has affected us long enough. Working together, we can ensure a healthier Montana.

The Montana Cancer Control Coalition (MTCCC) represents a broad spectrum of partners who want to reduce the burden of cancer in our state. They have worked together for over two years to develop Montana's Comprehensive Cancer Control Plan. The MTCCC includes cancer survivors, caregivers, medical professionals, hospital administrators, legislators, and representatives of nonprofits, the Department of Public Health and Human Services (DPHHS), private and public organizations, and other health advocates – all sharing their knowledge, experience and expertise.

We look forward to sustaining and expanding participation as the MTCCC moves forward toward implementation. For more information or to access the Plan online, visit <a href="https://www.cancer.mt.gov">www.cancer.mt.gov</a> or call 406-444-3624. To help control cancer in our state, join the MTCCC in implementing the Plan by completing and returning the Member Information Form or submit the form online.

Sincerely, Montana Cancer Control Coalition

Montana Comprehensive Cancer Control Plan, 2006-2011

Vision: A comprehensive, statewide, evidence-based approach to reduce the burden of cancer in Montana, motivated by compassion...an investment in the future.

## Mission:

1. To reduce cancer incidence, morbidity, and mortality in Montana through a collaborative partnership of private and public individuals and organizations.

- 2. To develop, implement, promote, and advocate for a statewide, coordinated, integrated approach to control cancer for all Montanans.
- 3. To ensure quality of life through prevention, early detection, treatment, research, rehabilitation, and palliation.

Purpose: The Comprehensive Cancer Control (CCC) Plan will serve as a guide for a Comprehensive Cancer Control Program for Montana. This is a participatory model that allows the involvement of all touched by cancer, and encourages statewide, community level participation. It has been designed to evolve with changing circumstances, and to allow flexible and creative responses to emerging issues. This plan will promote the collaboration needed to achieve comprehensive cancer control in Montana.

Guiding Principles: Best practices; comprehensive; cost sensitive; culturally sensitive; data driven; evidence based; evolutionary and responsive; outcome oriented; respectful

of the individual's rights, dignity, privacy, and safety.

My Fellow Montanans: It's likely that every one of us has been impacted by the burden and tragedy of cancer. It affects fathers and mothers, children, grandparents...and it could strike any of us tomorrow, next week, or a year from now.

The medical field has made great progress in the fight against cancer over the last decade, and I believe we are on the verge of breakthroughs on a number of social, medial and scientific fronts. Effective cancer prevention and control requires thorough, collaborative planning and coordination. The Montana Cancer Control Coalition has taken on that task. Over the last two years, this coalition has brought together hundreds of people from around our state. Together they have created a plan that will help prevent, reduce, and control cancer. These committed people shared their collective knowledge and expertise for the good of all. The result is this five-year Comprehensive Cancer Control Plan for Montana.

The plan is a living document, and one that will change and evolve over time. It is also a plan that honors our ability to make progress in our efforts to control a deadly disease. This is a process that can – and – should give us hope for the future. By working together, we can truly ensure a healthier Montana. (signed) Governor Brian Schweitzer.

This plan reflects the work of dozens of organizations and over 150 Montanans. They came together to share their time, knowledge and resources. Each and every one deserves our heartfelt appreciation for their unselfish investment in a healthier Montana.

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Executive Summary: Montana's CCC Plan 2006-2011

Cancer accounts for more than one in five Montana deaths.

Who: The Montana Cancer Control Coalition (MTCCC) is a diverse group of individuals and organizations working together to reduce cancer incidence, morbidity, and mortality for all Montanans through a statewide, coordinated, integrated approach to controlling cancer and ensuring quality of life and survivorship. The MTCCC has developed this Montana Cancer Control Plan with broad public involvement throughout the process and from public comments.

What: The CCC Plan is a guide for achieving the following overarching goals:

- 1. Work to prevent the incidence of cancer by reducing risk factors.
- 2. Detect cancer at the earliest stage possible.
- 3. Promote access to quality comprehensive cancer care.
- 4. Optimize the quality of life and survivorship for those affected by cancer.
- 5. Support research to best improve cancer control.
- 6. Monitor, disseminate and utilize cancer data while improving the consistency, coordination, and compliance of reporting and surveillance.
- 7. Monitor, document, and work to eliminate disparities across the cancer continuum.
- 8. Develop and support policies and initiatives that enable cancer control.

How: The CCC Plan describes priorities for cancer prevention and control activities in the following sections: Burden; Prevention; Early Detection; Treatment; Quality of Life and Survivorship; Research; Data, Registry and Surveillance; Advocacy; and Implementation, Evaluation and Evolution. In addition to the goals, objectives and strategies in each section, please note the "What You Can Do" lists.

This plan has a purpose beyond the identified goals and objectives. It is a living document that represents Montana's determination to prevent and control cancer. The objectives delineated in this plan are far-reaching and complex. The MTCCC is in the process of implementing this CCC Plan. No one individual or organization has the

capacity to carry out all of the activities. Please take this opportunity to help put the Montana CCC Plan into action by joining the MTCCC in preventing and controlling cancer. The member information form is at the end of this printed document and on the webpage at www.cancer.mt.gov. Why:

- 1. Montana's Central Tumor Registry records approximately 5,000 new cancer case per year. In 2003, there were 4,632 new cancer cases.
- 2. The overall annual cost of cancer to Montana is about \$588 million.
- 3. The American Cancer Society reports that more than 60 percent of all cancer deaths in the United States could be prevented.
- 4. National Cancer Institute predictions indicate that if current trends continue, 1/3 of all Americans will be diagnosed with cancer in their lifetimes.

The Plan: History and Next Steps.

Comprehensive Cancer Control (CCC) is "an integrated and coordinated approach to reduce cancer incidence, morbidity and mortality through prevention, early detection, treatment, rehabilitation and palliation." (CDC, 2002.)

The burden of cancer on Montana is tremendous. On average, 5,000 new cancer cases will be diagnosed annually in Montana. Cancer also stands as the second leading cause of death, taking approximately 1,800 Montana lives each and every year. No one is exempt from developing cancer, though age is a primary risk factor. About 77 percent of all cancers diagnosed will be among people aged 55 or older. The good news is that advances in screening, early detection, cancer treatment, and follow-up care are allowing more people to live "beyond" cancer each year. While progress has been made to reduce cancer incidence and mortality, significant challenges still lie ahead. At the same time, fiscal constraints are driving cancer-related programs and organizations at all levels to find smarter, more effective and efficient ways to fight the disease.

There is a strong national initiative to include cancer control in public health activities. This dialogue on cancer began several years ago, and has grown into a national movement to initiate formal, state-level comprehensive cancer control planning efforts, primarily funded by the Center for Disease Control and Prevention (CDC). Cancer control plans become the stepping stones for advancing cancer prevention and control. State and tribal governments have been encouraged to develop their own plans to address their own unique cancer burdens and resources.

In October 2003, Montana began creating its Comprehensive Cancer Control Plan. The people who came together became the Montana Cancer Control Coalition, which is comprised of survivors, medical professionals, hospital administrators, representatives of nonprofits, staff from the Cancer Control Section of the Department of Public Health and Human Services (DPHHS), organizational representatives, and others. This planning group recognized common threads. These included the need to enhance

education, communication, survivorship, knowledge of resources, and to identify barriers to availability, accessibility, and utilization of services. Defining the burden of cancer and healthcare disparities were considered key first steps to the prevention and reduction of cancer. The MTCCC recognizes the special circumstances of American Indians with regard to cancer disparities, access to healthcare, self governance, and cultural uniqueness. The language of the plan is deliberately broad; references to patients, healthcare providers, and health facilities are intended to be inclusive of all residents of Montana.

The MTCCC has been working together to identify and prioritize areas of need and challenge in Montana's efforts to prevent and control cancer. In 2004, on behalf of the Montana Cancer Control Coalition, the Montana Department of Public Health & Human Services (DPHHS) entered into a cooperative agreement with the Centers for Disease Control and Prevention. Funds were provided to Montana to develop this Comprehensive Cancer Control (CCC) Plan.

The MTCCC prioritized cancer-control issues for Montana. Goals, measurable objectives and data sources were established for each issue. Coalition members reviewed, revised, and approved a draft plan. The public was then invited to review the plan and to submit their comments. A summary is available online at www.cancer.mt.gov.

A Guide for Statewide Cancer Prevention and Control.

The Plan...Next Steps:

Montana's CCC Plan covers the five-year period between 2006 and 2011. It offers a framework for statewide cancer prevention and control, utilizes evidence-based strategies, and sets priorities for public and private cancer control activities.

The goals, objectives, and strategies are provided for each section of this plan are designed to serve as a guide and a call to action. No one document can cover all cancer sites, treatment protocols, or emerging best practices, but this plan attempts to include the sites, interventions, and issues that research suggests will impact cancer incidence, morbidity, mortality, and quality of life. The intent is to engage individuals and organizations involved in any aspect of cancer control in the process of implementing this plan.

The CCC Plan is designed to serve as a living document that can guide unified and collaborative action. It will be modified as the state moves into implementation, as evidence and needs change, and as new issues emerge.

The success of this document and Montana's efforts to prevent and control cancer depends on translating strategies into action. To do so will require substantial indivudal and organizational involvement throughout the state.

We welcome your active involvement in implementing this plan and in breathing life into a sustainable effort. We've set some lofty goals, but they are achievable if we work together. We can turn this plan into reality.

A membership form is included at the end of the printed plan and on the Cancer Control webpage www.cancer.mt.gov. Please complete and return it.

The comprehensive approach to cancer control is an emerging strategy that seeks to ensure that all of a state's cancer-fighting resources, from government programs to private organizations, are working together to fight cancer in every community, on all fronts, from prevention and early detection to treatment, rehabilitation, and end-of-life care. (The Council on State Governments).

The Benefits of Comprehensive Cancer Control:

- 1. Maximizes resources
- 2. Reduces duplication of efforts
- 3. Enables changes in systems and policies
- 4. Enables multi-level, simultaneous interventions
- 5. Maximizes impact on reducing incidence and mortality, and improving quality of life.

## Montana's CCC Plan Goals at a Glance:

- 1. Prevention: Reduce the risk factors that lead to cancer, e.g., tobacco, poor nutrition, inactivity, obesity, ultraviolet light exposure, and environmental carcinogens.
- 2. Early Detection: Broaden coverage, increase utilization, and promote compliance with cancer-screening guidelines.
- 3. Treatment: Ensure prevailing standards of care, accessibility, availability, and utilization of cancer treatment services for all. Promote optimum patient/provider communication.
- 4. Quality of Life & Survivorship: Promote quality of life for cancer patients; empower patients and families; ensure age-appropriate services for children; and ensure opportunities for safe and effective use of complementary medicine.
- 5. Research: Provide access to cancer research information and ensure high-quality cancer research.
- 6. Data, Registry & Surveillance: Collect, analyze, and disseminate quality cancer-related data.
- 7. Advocacy: Implement Montana's Comprehensive Cancer Control Plan.

### The Burden of Cancer:

Rates: According to the National Cancer Institute, cancer incidence rates in Montana continue to rise, as they have since 1990. In 2003, the Montana incidence rate was 472.0 per 100,000, as compared to the United States incidence rate, which was 471.4 per 100,000. The actual number of cancer incidences are converted to age-adjusted rates per 100,000. This allows comparison of Montana data with that of other states

and the nation.

Disparities: As is clear from the graph described below, there are grave disparities between the Montana cancer rates for American Indian and White populations and between men and women. In general, rates among men tend to be higher than those among women, and higher among American Indians than among Whites. American Indian men exhibit the highest cancer incidence rates of all four groups.

Description of figure: Montana Cancer Incidence Rates: White and American Indian by Gender. (Please note that actual data for this line graph were unavailable, so this description estimates each data point. In 1991-1993, the incidence of cancer for White females was about 362 per 100,000. The incidence of cancer for Native American females was about 442 per 100,000. The incidence of cancer for White males was about 512 per 100,000. The incidence of cancer for American Indian males was about 618 per 100,000. In 1994-1996, the incidence of cancer for White females was about 380 per 100,000. The incidence of cancer for American Indian females was about 510 per 100,000. The incidence of cancer for White males was about 511 per 100,000. The incidence of cancer for American Indian males was about 759 per 100,000. In 1997-1999, the incidence of cancer for White females was about 412 per 100,000. The incidence of cancer for American Indian females was about 556 per 100,000. The incidence of cancer for White males was about 530 per 100,000. The incidence of cancer for Native American males was about 709 per 100,000. In 2000-2002, the incidence of cancer for White females was about 418 per 100,000. The incidence of cancer for American Indian females was about 530 per 100,000. The incidence of cancer for White males was about 559 per 100,000. The incidence of cancer for American Indian males was about 730 per 100,000. End of description.

National studies suggest that poverty may be one of the root causes of this inequity and

that disparities in cancer incidence rates are driven by a complex set of social, economic, cultural, and health system factors. Disease always occurs within the context of human circumstances, including social position, economic status, culture, and environment. Poverty, culture and social injustice are believed to be the three principle determinants of cancer disparities. These factors are interrelated and, to some extent, superimposed. (Source: Poverty, Culture, and Social Injustice: Determinants of Cancer Disparities. Harold P. Freeman, MD. CA: A Cancer Journal for Physicians. Online: http://amcacersoc.org).

Incidence: The average incidence of cancers in Montana, grouped according to anatomical site, reveals that the four most common types of invasive cancer are prostate, breast, lung/bronchus, and colorectal. Cumulatively, these four cancers account for 56.8 percent of all diagnosed invasive cancers in Montana. Adding cancer of the bladder (including in-situ cases), non-Hodgkin lymphoma, uterus, and all leukemia brings the cumulative total to 70.7 percent. (Montana Central Tumor Registry: 1999- 2003.)

Five-year averages for Montana males (1999 to 2003) reveal that three cancer sites: prostate (33.2%), lung/bronchus (14.3%), and colorectal (10.4%), account for 57.9 percent of all cancer incidences, as compared to 56.8 percent for males in the U.S. (CDC, 2001). Five-year averages for Montana females reveal that three cancer sites: breast (30.8%), lung/bronchus (13.6%), and colorectal (11.0%), account for 54.4 percent of all incidences, as compared to 56.0 percent for females in the U.S. (CDC, 2001).

Stage: Stage at the time of cancer diagnosis is an important predictor of the outcome of treatment. The earlier cancer is diagnosed, the better the chances of survival. Between 1999 and 2003, 46 percent of all cancers diagnosed in Montana residents were at a local stage, 22 percent were regional (spreading beyond the organ of origin but remaining within the anatomical region), and 18 percent were diagnosed at a distant (metastasized) stage. The majority of prostate (70%) and breast (63%) cancers were diagnosed at a local stage. With colorectal cancer, 37 percent were diagnosed at a local stage; with lung cancers, only 16 percent were diagnosed at a local stage.

Five-Year Cancer Survival in Montana: The five-year relative survival rate is the percent

of patients surviving five years after diagnosis. The description of the following table shows the Montana survival rate in comparison with the United States rate. Survival rates are for all sites, as well as for prostate, breast, colorectal and lung.

Description of Table: Five-year Survival Rates in Montana. Survival rate for all stages and all sites was 66%. For all stages of prostate cancer, survival rate was 98.7%. For all stages of breast cancer, survival rate was 90.6%. For all stages of colorectal cancer, survival rate was 66.8%. For all stages of lung/bronchus cancer, survival rate was 14.3%. Survival rate for localized cancer of all sites was 94.8%. Survival rate for localized prostate cancer was 100%. Survival rate for localized breast cancer was 97.7%. Survival rate for localized colorectal cancer was 92.7%. Survival rate for localized lung/bronchus cancer was 46.6%. Survival rate for regional cancer of all sites was 62.8%. Survival rate for regional prostate cancer was 100%. Survival rate for regional breast cancer was 86.9%. Survival rate for regional colorectal cancer was 69.7%. Survival rate for regional lung/bronchus cancer was 16.8%. Survival rate for distant cancer of all sites was 20.9%. Survival rate for distant prostate cancer was 29.4%. Survival rate for distant breast cancer was 20.9%. Survival rate for distant colorectal cancer was 10.8%. Survival rate for distant lung/bronchus cancer was 2.1%.

Five-year Survival Rates in the U.S.. Survival rate for all stages and all sites was 66.3%. For all stages of prostate cancer, survival rate was 99.9%. For all stages of breast cancer, survival rate was 89.1%. For all stages of colorectal cancer, survival rate was 65.6%. For all stages of lung/bronchus cancer, survival rate was 15.7%. Survival rate for localized cancer of all sites is unavailable. Survival rate for localized prostate

cancer was 100%. Survival rate for localized breast cancer was 97.7%. Survival rate for localized colorectal cancer was 90.4%. Survival rate for localized lung/bronchus cancer was 49.5%. Survival rate for regional cancer of all sites is unavailable. Survival rate for

regional prostate cancer was 100%. Survival rate for regional breast cancer was 81.3%.

Survival rate for regional colorectal cancer was 67.9%. Survival rate for regional lung/bronchus cancer was 16.2%. Survival rate for distant cancer of all sites is unavailable. Survival rate for distant prostate cancer was 33.5%. Survival rate for distant breast cancer was 26.1%. Survival rate for distant colorectal cancer was 9.7%. Survival rate for distant lung/bronchus cancer was 2.1%. U.S. rates are from SEER (Statistics, Epidemiology, and End Results) 1995-2001. Five year survival for all sites by

stage at diagnosis is not available for the U.S. End of description. Stages of Cancer:

- 1. A localized cancer is limited to the site of origin. There is no evidence of metastasis elsewhere in the body.
- 2. A regional cancer extends beyond the limits of the site of origin into surrounding organs or tissues or regional lymph nodes.
- 3. A distant cancer extends beyond adjacent organs, metastasizes to distant sites, or to distant lymph nodes.

Mortality: Cancer is the second leading cause of death in Montana, and accounted for 21.8 percent of all 2003 deaths in Montana. Nationally, cancer accounted for 22.8 percent of all deaths in 2002. There are approximately 1,880 cancer deaths annually in Montana. These include cancers of the lung, bronchus and trachea (30%), colon and rectum (9%), prostate (6%), and breast (6%), which together accounted for 50 percent of Montana's 2003 cancer deaths. The age-adjusted cancer mortality rate (1999 . 2003) for all cancer sites (including prostate, breast, lung, colorectal, and others) combined was 190.8 per 100,000. This is relatively consistent with national rates of 197.8 per 100,000.

Description of figure: Montana Observed Mortality Rates. This line graph shows deaths per 100,000 resident population by year for all races and ages. Figures for breast cancer are for females only. Figures for prostate cancer are for males only. Figures for lung/bronchus and colorectal cancers are for both genders. Data source is http://statecancerprofiles.cancer.gov. In 1978, the rate of deaths from lung/bronchus cancers was 38.0. In 1980, it was 43.9. In 1985, it was 44.6. In 1990, it was 50.4. In 1995, it was 50.5. In 2000, it was 49.5. In 2002, it was 51.9. In 1978, the rate of deaths from breast cancer was 29.5. In 1980, it was 26.2. In 1985, it was 28.1. In 1990, it was 34.1. In 1995, it was 33.9. In 2000, it was 24.8. In 2002, it was 27.1. In 1978, the rate of deaths from prostate cancer was 43.5. In 1980, it was 34.7. In 1985, it was 43.4. In 1990, it was 40.6. In 1995, it was 35.7. In 2000, it was 27.8. In 2002, it was 27.6. In 1978, the rate of deaths from colorectal cancers was 26.6. In 1980, it was

26.9. In 1985, it was 26.4. In 1990, it was 21.5. In 1995, it was 19.0. In 2000, it was 20.1. In 2002, it was 17.7. End of description.

Heart disease remains the leading cause of death in Montana, at 23.4 percent in 2003.

## The Financial Burden of Cancer

In 2002, cancers cost this country over \$179 billion overall. This includes more than \$110 billion for lost productivity and over \$60 billion for direct medical costs (CDC, 2003). Each year breast cancer treatment costs nearly \$7 billion; colorectal cancer treatment costs about \$6.5 billion; and cervical cancer treatment costs about \$2 billion. Overall, cancer costs Montana approximately \$588 million annually (2002).

"Half of all bankruptcies in the United States are the result of a medical diagnosis." (Mary Zapor, Pancreatic Cancer Action Network.)

Description of table: Montana men, 2003 cancer cases and cancer deaths. Total number of cancer cases was 2,539. Total number of cancer deaths was 961. Prostate cancer accounted for 34% of cancer cases and 11% of cancer deaths. Lung & bronchial cancer accounted for 14% of cancer cases and 31% of cancer deaths. Colon & rectal cancer accounted for 8% of cancer cases and 8% of cancer deaths. Urinary bladder cancer accounted for 8% of cancer cases and 4% of cancer deaths. Leukemia accounted for 3% of cancer cases and 5% of cancer deaths. Non-Hodgkin lymphoma accounted for 3% of cancer cases and 4% of cancer deaths. Kidney cancer accounted for 3% of cancer cases and 3% of cancer deaths. Melanoma skin cancer accounted for 3% of cancer cases and 3% of cancer deaths. Oral cavity cancer accounted for 3% of cancer cases and 2% of cancer deaths. Pancreatic cancer accounted for 2% of cancer cases and 5% of cancer deaths. Esophageal cancer accounted for 1% of cancer

cases and 4% of cancer deaths. Liver & bile duct cancer accounted for 1% of cancer cases and 3% of cancer deaths. Cancer of all other sites accounted for 17% of cancer cases and 17% of cancer deaths. End of description.

Description of table: Montana women, 2003 cancer cases and cancer deaths. Total number of cancer cases was 2,093. Total number of cancer deaths was 877. Breast cancer accounted for 31% of cancer cases and 13% of cancer deaths. Lung & bronchial cancer accounted for 14% of cancer cases and 27% of cancer deaths. Colon & rectal cancer accounted for 11% of cancer cases and 10% of cancer deaths. Uterine cancer accounted for 5% of cancer cases and 2% of cancer deaths. Non-Hodgkin lymphoma accounted for 4% of cancer cases and 5% of cancer deaths. Thyroid cancer accounted for 4% of cancer cases and 2% of cancer deaths. Melanoma skin cancer accounted for 3% of cancer cases and 2% of cancer deaths. Ovarian cancer accounted for 3% of cancer cases and 6% of cancer deaths. Pancreatic cancer accounted for 2% of cancer cases and 5% of cancer deaths. Leukemia accounted for 2% of cancer cases

and 4% of cancer deaths. Kidney & renal pelvic cancer accounted for 2% of cancer cases and 2% of cancer deaths. Urinary bladder cancer accounted for 2% of cancer cases and 1% of cancer deaths. Multiple myeloma accounted for 1% of cancer cases and 2% of cancer deaths. Brain and other nervous system cancer accounted for 1% of cancer cases and 3% of cancer deaths. Cancer of all other sites accounted for 15% of cancer cases and 18% of cancer deaths. End of description.

Note: For both men and women, the data exclude basal and squamous cell skin cancers and in-situ carcinomas except urinary bladder. Data Source: Montana Central Tumor Registry, 2005.

On an individual level, the foundation for effective cancer prevention and control is a trusting relationship with a personal primary care physician or healthcare provider.

Prevention: Many cancers are preventable. Scientists estimate that as many as 50 to 75 percent of cancer deaths in the United States are caused by various environmental factors. Environmental causes include lifestyle choices as well as exposure to agents in the air and water. Cancer is linked to some behavioral choices such as smoking, physical inactivity and poor diet. Although some cancer prevention takes place at the individual level, it is our society's responsibility to prevent public exposure to environmental carcinogens and to help facilitate healthy lifestyles for all citizens. It is also important to acknowledge the interplay among behavior and economic, environmental, social, and cultural factors when looking at cancer prevention.

The Top Six Ways to Prevent Cancer:

- 1. Avoid the use of tobacco.
- 2. Choose a diet rich in fruits and vegetables.
- 3. Decrease exposure to environmental carcinogens
- 4. Engage in regular physical activity.
- 5. Maintain a healthy body weight.
- 6. Protect your skin from ultraviolet exposure.

Each year, at least one-third of all cancer deaths and one-fifth of all deaths can be attributed to tobacco use. Smoking is the single most preventable cause of death in the United States, yet one in five adult Montanans currently smokes cigarettes. Another six percent use smokeless tobacco. Nationally, about 170,000 people died of cancer because of tobacco use in 2002. This number represents at least 30 percent of all estimated cancer deaths in the United States.

People whose diets are rich in fruits and vegetables are likely to have a lower risk of cancer of the colon, mouth, pharynx, esophagus, stomach, lungs, and possibly prostate. Experts recommend between five and nine servings of fruits and vegetables daily. These choices can hinge on more than good intentions: dietary choices may come down to the ability to afford fruits and vegetables.

An estimated 20 to 30 percent of the most common cancers may be related to excess weight and physical inactivity. Recent studies indicate that overweight and obesity may also increase the risk of death from many cancers, accounting for up to 14 percent of cancer deaths in men and 20 percent in women. Obesity prevention can also reduce the risk for many of the most common cancers, including colon, uterine, renal cell, and postmenopausal breast cancers. Regular physical activity is also associated with reduced risk of heart disease, high blood pressure, diabetes, obesity, and some cancers. Despite the benefits, only one in four children engages in the recommended level of daily physical activity (30 minutes of moderate activity or 20 minutes of vigorous activity).

The self-reported rate of overweight adults in Montana increased from 41.7 percent in 1990 to 56.9 percent in 2003. The self-reported rate of obesity increased from 8.7 percent in 1990 to 18.8 percent in 2003. Both rates remained steady between 2001 and 2003.

Skin cancer is the most common cancer in the United States. Rates are increasing despite the fact that the greatest risk factor for skin cancer is avoidable, unprotected exposure to ultraviolet (UV) rays. Reducing long-term exposure to the sun and artificial light from tanning beds, booths, and sun lamps reduces the risk of non-melanoma skin cancer. Avoiding burns and other damage from these sources, especially during childhood and adolescence may also reduce the chances of developing melanoma skin cancer. White people have the highest risk of contracting melanoma skin cancer, with white males the highest risk group of all. Death rates from melanoma skin cancer are twice as high in males as in females.

Other cancer prevention involves social responsibility and the prevention of public and occupational exposure to environmental carcinogens. The National Cancer Institute regularly updates the Report on Carcinogens, which lists more than 200 chemicals known or suspected of causing cancer. For more information, visit: http://ntp-server.niehs.nih.gov or http://progressreport.cancer.gov.

Goal I: Reduce the impact of tobacco use and exposure to secondhand smoke on the burden of cancer in Montana.

Objective I.1: Decrease the prevalence of tobacco use among adults and youth.

Baseline:

Adults: Smoking (21%); smokeless (6%) Youth: Smoking (19%); smokeless (9%)

Outcomes, by 2011:

Adults: Smoking (12%); smokeless (3%) Youth: Smoking (16%); smokeless (7%).

Data Sources: Behavioral Risk Factor Surveillance System (BRFSS) 2004; Youth Risk Behavior Survey (YRBS) 2003; Prevention Needs Assessment (PNA) 2004

Strategy 1: Plan, develop, and implement statewide public awareness and education campaigns on the need for increased tobacco product prices; to reduce tobacco-industry sponsorship of community events; and to remove preemption related to tobacco product placement.

Strategy 2: Educate and encourage Tribal governments to adopt tobacco tax and/or revenue sharing agreements to reduce tobacco sales and use.

Strategy 3: Determine and implement appropriate policies to increase the tobacco tax.

Strategy 4: Collaborate with Office of Public Instruction (OPI) and individual school districts to develop and implement comprehensive tobacco-free school policies

Strategy 5: Increase cessation attempts by designing and implementing strategies to increase utilization of the Montana Tobacco Quit Line (1-866-485-QUIT).

Strategy 6: Increase the number of healthcare providers who integrate the U.S. Public Health Department's Clinical Guidelines: "Treating Tobacco Use and Dependence" into their healthcare systems.

The American Cancer Society estimates there will be 168,140 cancer deaths in the United States annually that can be directly attributed to tobacco use. This number represents about 30% of all estimated U.S. cancer deaths. Annually, approximately 1,400 Montanans will die of diseases directly attributable to tobacco use. Approximately 90% of current adult smokers became addicted at, or before, age 18.

Profile: Penny Patterson started smoking in 1951, at age 16. No one objected. Her father and mother were smokers. When she got married at 18, her husband was a smoker, too. Years passed. Children came along and grew up. Cigarettes were a constant part of the everyday woof and warp of life, their legacy evident in burn marks on furniture, yellowed walls that only became obvious next to fresh paint, the sound of her husband's cough. Then one day, an old friend was diagnosed with cancer. If she got out of the hospital, her children would always have to care for her. Sitting in the hospital room, it occurred to Penny that if she became old and sick and her children had to care for her, she wouldn't be able to live with herself if it was because of something she'd done to herself. She threw away her cigarettes as she left the hospital. "I still miss smoking sometimes, but this was the greatest gift I could give my kids."

Objective I.2: Reduce Montanans' exposure to secondhand tobacco smoke.

#### Baseline:

Children: 17 percent of children under 18 are potentially exposed to secondhand tobacco smoke at home.

Schools: 29 percent of schools are tobacco free (2002).

Workplaces: 82 percent of worksites have formal policies that prohibit smoking (2001).

Nonsmokers: A percent to be determined of nonsmokers are regularly exposed to

secondhand tobacco smoke.

Outcomes: By 2007, determine the percentage of nonsmokers, including children, who are regularly exposed to secondhand tobacco smoke. By 2011, less than 10 percent of children will be regularly exposed to tobacco smoke at home (Healthy People 2010 target); all schools will be tobacco free; all worksites will have formal policies that prohibit smoking; less than 45 percent of nonsmokers will be regularly exposed to secondhand tobacco smoke (Healthy People 2010 target).

Data sources: Behavioral Risk Factor Surveillance System, 2002 (BRFSS); Youth Risk Behavior Survey, 2003 (YRBS); Montana Adult Tobacco Survey (MT-ATS) 2004.

Strategy 1: Determine the percentage of nonsmokers who are regularly exposed to secondhand tobacco smoke.

Strategy 2: Plan, develop, and implement a statewide public education and awareness campaign regarding the hazards of exposure to secondhand smoke.

Strategy 3: Increase the number of community-based public education and awareness campaigns delineating the hazards of exposure to secondhand smoke.

Strategy 4: Increase the number of policies and laws eliminating exposure to secondhand smoke by supporting:

A. the limited 2005 statewide Secondhand Smoke Free Law to become all inclusive in 2009.

B. self-governing community/county secondhand smoke free ordinances.

C. tribal nation's secondhand smoke-free policies.

D. voluntary secondhand smoke-free policies.

E. comprehensive tobacco-free school policies.

Strategy 5: Support the Montana Tobacco Use Prevention Strategic Plan.

According to the American Cancer Society, approximately 38,000 nonsmoking Americans die every year as a result of exposure to secondhand smoke . 120 of them are Montanans. Nonsmokers exposed to secondhand(environmental) tobacco smoke absorb nicotine and other compounds just as smokers do. The U.S. Environmental Protection Agency (EPA) has classified secondhand smoke as a Group A carcinogen, which means that evidence exists that it causes cancer in humans (American Cancer Society).

Objective I.3: Increase the total funding for the Montana Tobacco Use Prevention Program (MTUPP) and expand the program to meet national standards.

Description of table: Baselines and Outcomes. Baseline: 2006 state funding level is \$6,889,920. CDC funding is \$285,000. Total is \$7,174,920. 2007 state funding level is \$6,804,480. CDC funding is \$616,500. Total is \$7,420,980. Outcomes: In 2009, \$9.35 million (CDC recommended minimum) will be available. In 2011, MTUPP will meet national recommendations for a comprehensive, evidence-based program as in the Guide to Community Preventive Services: Tobacco Use Prevention and Control.

Data source: MTUPP 2005. End of description.

AToday-s teenager is tomorrow-s potential regular customer...the smoking patterns of teens are particularly important to Phillip Morris.@ (Philip Morris Companies, Inc.,1981 <a href="https://www.who.int/tobacco/en/atlas7.pdf">www.who.int/tobacco/en/atlas7.pdf</a>).

Strategy 1: Advocate for allocation of a larger percent of tobacco settlement funds for a comprehensive tobacco use prevention and control program.

Strategy 2: Plan, develop, and implement a campaign to educate the public and decision-makers on the need for a comprehensive tobacco use prevention and control program.

Strategy 3: Determine and implement the appropriate policy vehicle to increase the total funding available for implementation of a comprehensive tobacco use prevention program to at least the minimum level recommended by the Centers for Disease Control and Prevention (CDC).

Strategy 4: Expand the MTUPP as funding allows. Increase:

A. the number of public education and awareness campaigns on tobacco issues.

- B. the number of school-based interventions.
- C. training and technical assistance to community-based programs and their coalitions.
- D. services provided by the Montana Tobacco Quit Line to meet the needs of a greater number of tobacco users.
- E. surveillance on tobacco issues.
- F. evaluation of all components of the MTUPP.

Strategy 5: Collaborate with the Office of Public Instruction, the Addictive and Mental Disorders Division, the Department of Revenue, and the Department of Justice to address various tobacco-related issues in Montana, and add a chronic disease prevention component to tobacco use prevention efforts.

Tobacco Industry Influence in Montana: The tobacco industry spends more than \$12.4 billion per year B over \$34.1 million a day B marketing its deadly products in the United States alone, much of this advertising reaches kids. The annual tobacco industry marketing expenditures for Montana are \$40.7 million.

Research has found that: kids are three times more sensitive to tobacco advertising than adults; kids are more likely to be influenced to smoke by cigarette marketing than by peer pressure; and one-third of underage experimentation with smoking is attributable to tobacco company advertising (www.tobaccofreekids.org).

Goal II: Reduce the impacts of poor nutrition, physical inactivity and obesity on the burden of cancer in Montana.

Objective II.1: Increase the percentage of youth and adults who consume the recommended number of servings of fruits and vegetables per day

Baseline: 16.7% of students in grades 9-12 and 22% of adults reported eating five or

more servings of fruits and vegetables per day during the past seven days Outcomes: By 2011, 19% of students in grades 9-12 and 25% of adults will report eating five or more servings of fruits and vegetables per day.

Data sources: YRBS 2003; BRFSS 2003.

Strategy: 1 Promote inclusion of cancer risk reduction diets in school health education curriculums, nutritional and meal programs, and health promotion information.

Strategy 2: Promote and support environmental changes in school and child care programs to increase the availability and promotion of fruits and vegetables.

Strategy 3: Promote and support school, home, and community garden projects.

Strategy 4: Support community wide campaigns and projects geared to youth and families that promote the consumption of fruits and vegetables.

Strategy 5: Support the Women, Infants and Children (WIC) Farmer-s Market Nutrition Program to increase access to fruits and vegetables for families.

Strategy 6: Support worksite programs designed to increase fruit and vegetable consumption.

Strategy 7: Promote community education and public awareness campaigns on healthy eating for cancer risk reduction and cancer prevention; distribute the Cancer Research and Prevention Foundation-s "Progress Through Prevention" educational materials. Strategy 8: Collaborate with industry partners to increase access to, and availability of, fruits and vegetables on a communitywide level.

Five to Nine a Day for Better Health is a national program that seeks to increase the number of daily servings of fruits and vegetables Americans eat to five or more. Diets rich in fruits and vegetables may reduce the risk of cancer and other chronic diseases. Fruits and vegetables provide essential vitamins and minerals, fiber, and other substances that are important for good health. (Source: www.5aday.gov)

Description of Table: Fruits and vegetables....how many times a day do you eat fruits and vegetables? In 2002, compared to 4.7% of all Americans, 4.1% of Montanans never ate fruits and vegetables or ate fewer than one per day. Compared to 35.9% of all Americans, 34.1% of Montanans ate one to two servings of fruits and vegetables per day. Compared to 36.1% of all Americans, 39.1% of Montanans ate three to four servings of fruits and vegetables per day. Compared to 22.6% of all Americans, 22.7% of Montanans ate five or more servings of fruits and vegetables per day. Source: <a href="http://apps.nccd.cdc.gov/5ADaySurveillance">http://apps.nccd.cdc.gov/5ADaySurveillance</a>. End of description.

For more information on healthy diet, go to <a href="http://MyPyramid.gov">http://MyPyramid.gov</a> .

## Objective II.2: Increase:

- 1. the percentage of adults and youth who engage in moderate and vigorous physical activity.
- 2. the amount of leisure time activity pursued by adults.
- 3. the percentage of youth spending less than 2 hours per school day watching television.

Baseline: BRFSS 2003; YRBS 2003.

Youth:

- 1. 22.3 percent of 7th and 8th graders participate in moderate physical activities; 71.8 percent participate in vigorous physical activities.
- 2. 24 percent of 9th-12th graders participate in moderate physical activities; 62.1 percent engage in vigorous physical activities.
- 3. 69 percent of 7th-8th graders watch less than 2 hours of television on an average school night.
- 4. 49.5% of 9th-12th graders watch less than 2 hours of television on an average school night

## Adults:

- 1. 58.5% engage in moderate physical activities
- 2. 33.2% engage in vigorous physical activities
- 3. 79.8% report engaging in leisure time physical activity

Outcomes: By 2011,

Youth:

- 1. 35 percent of 7th-12th graders will participate in moderate physical activities; 85 percent will participate in vigorous physical activities (Healthy People 2010 target).
- 2. 75 percent of 7th-12th graders will watch less than 2 hours of television on an average school night (Healthy People 2010 target).

#### Adults:

- 1. 60% will engage in moderate physical activities
- 2. 35% will engage in vigorous physical activities.
- 3. 82% will report engaging in leisure time physical activity

Data sources: BRFSS, 2003; YRBS, 2003; Healthy People 2010.

Strategy 1: Support and promote the development and implementation of community wide campaigns:

A. to increase physical activity in youth and adults, and to include education on cancer risk reduction and prevention activities.

B. geared to parents that focus on limiting total television screen time for children to two hours or less per day.

C. to increase private and public sector opportunities for adult physical activities with Apoint of decision prompts.

Strategy 2: Support policies for school wellness and physical education programs.

Strategy 3: Promote and support school, after school, youth-based, and childcare programs that increase opportunities for physical activity.

Strategy 4: Support partnerships with community leaders and stakeholders that support physical activity policies in schools, childcare programs, community organizations and worksites. Support local campaigns to create safe walk, run and bike paths.

Strategy 5: Identify communities and worksites promoting cancer risk reduction by

providing health education and physical activity programs.

Strategy 6: Promote fitness activities in employee work site wellness programs and increase work sites offering wellness programs.

Strategy 7: Identify barriers and implement strategies to promote policies promoting physical activity.

Strategy 8: Work with healthcare professionals, local health departments, and community clinics to support exercise counseling and distribution of exercise plans.

Objective II.3: Maintain the current rate of self-reported overweight and obesity in Montana.

Baseline: Adults: 57% are overweight; 18.8% are obese.

Youth: 8.1% are overweight; 11.6% are at risk for becoming overweight.

Outcomes: By 2011, there will be no rise in the percentage of overweight or obese

adults, or in the percentage of overweight or at-risk youth.

Data sources: YRBS 2003; BRFSS 2003.

Strategy 1: Design a strategy to educate healthcare providers to screen all adult patients for obesity and offer intensive weight management counseling and behavioral interventions for those who are.

Strategy 2: Collaborate with the Montana Cardiovascular Disease/Obesity Prevention Task Force to study obesity control and to formulate statewide policies and strategies for children, youth, and adults. Support implementation of their statewide plan.

Strategy 3: Support surveillance of Body Mass Index (BMI) changes in Montana for adults, youth, and children.

Strategy 4: Support employers in the development of worksite wellness programs.

Strategy 5: Educate healthcare providers and the public on the link between cancer and

obesity.

Strategy 6: Support the development of community coalitions and networks to assess, monitor and develop strategies for obesity prevention in local communities and to promote healthful eating and physical activity.

Goal III: Reduce the incidence of skin cancer in Montana.

Objective III.1: Reduce the percentage of adults who report sunburn during the past 12 months.

Baseline: 41.1% of adults report having had a sunburn during the past 12 months

Outcomes: By 2011, less than 35% of adults will report having had a sunburn during the

past 12 months.

Data sources: BRFSS 2004

Strategy 1: Distribute educational and culturally relevant materials on skin cancer prevention at parks and other recreational areas throughout the state. Distribute materials on sun cover-up behaviors that include photos of skin cancers, sun-safety guidelines, and other information.

Strategy 2: Promote the increase of shaded areas at public recreational sites.

Strategy 3: Add questions to the BRFSS every other year dealing with the protective effects of limited sun and UV light exposure, wearing protective clothing, and using sun screen.

Objective III.2: Increase the number of school programs that educate students on decreasing exposure to UV light and skin cancer prevention.

Baseline: To be determined.

Outcomes: By 2008, establish the number of school programs addressing skin cancer prevention. By 2011, increase the number of programs by a percentage to be determined.

Data sources: To be established.

Strategy 1: Establish how many school programs on skin cancer prevention there are in Montana (consider adding a question to the School Administrators Self Assessment Survey).

Strategy 2: Support school, preschool, and youth programs designed to increase sun protective knowledge, attitudes, intentions, and behaviors among children and youth.

Strategy 3: Promote family-based interventions such as "Together for Sun Safety".

Tips for Safe Fun in the Sun:

- 1. Avoid the sun between 10 a.m. and 3 p.m., even on cloudy days.
- 2. Kids should wear photo-protective clothing and wide-brimmed hats. Sit in the shade when outdoors.
- 3. Use waterproof sunscreen and lip balm with an SPF of 15 or higher routinely on yourself and your children, and reapply it every two hours.
- 4. Babies under six months of age should not spend much time in the sun. (source: <a href="http://www.PreventCancer.org">http://www.PreventCancer.org</a>)

Goal IV: Reduce the risk of cancer from exposure to environmental carcinogens.

Objective IV.1: Increase compliance with new arsenic standards in public drinking water and private wells.

Baseline: In 2004, the levels of arsenic were above 10 parts per billion (ppb) in 29 of 2,050 public water supplies, affecting 5,075 people. In a sampling of private wells, 10% of 3,541 had arsenic levels above 10 ppb (Montana Bureau of Mines, March 2005).

Outcomes: By 2009, all public water supplies in Montana will comply with the standard of 10 ppb arsenic maximum, and there will be an increase in arsenic testing by private well owners.

Data sources: Public water supplies: Department of Environmental Quality (DEQ) Public Water Supplies Program; well tests, Montana Bureau of Mines.

Strategy 1: Work with the DEQ and the Water Quality Testing program to monitor compliance with arsenic standards in public water supplies and encourage private well users to test their drinking water for exposure.

Strategy 2: Support the Heavy Metals Workgroup to increase knowledge about arsenic exposure in drinking water and to establish regional baselines for exposure levels. Strategy 3: Promote education on testing water for arsenic and inform the public about methods to reduce their exposure to arsenic.

Objective IV.2: Increase awareness of the potential danger of high radon exposure in homes and workplaces; decrease the proportion of homes with radon levels in excess of 4pCi/L.

Baseline: Level of awareness to be determined.

Outcomes: By 2006, establish baseline estimates of public awareness of radon. By 2011, increase the level of awareness of radon by a percentage to be determined. Data sources: BRFSS.

Radon found in homes may contribute to as many as 20,000 lung cancer deaths in the U.S. annually. Reducing indoor radon exposure could prevent about 30 percent of lung cancer deaths from radon. Of these, 86 percent would be smokers or former smokers. Forty-seven percent of homes in Montana have radon levels in excess of >4pCi/L. [U.S. Environmental Protection Agency guidelines for maximum exposure] (1997 Radon Study, Montana State University).

Strategy 1: Work with Montana labs or the National Institute for Occupational Safety and Health at CDC to determine number of houses and workplaces tested for radon each year and to document the percent of homes and workplaces with exposure to elevated radon >4pCi/L.

Strategy 2: Work with existing agencies and organizations to determine the number of existing homes with elevated radon levels that have undergone mitigation, and newly built homes with radon-resistant new construction features.

Strategy 3: Design and implement strategies to increase public awareness of the potential dangers of high radon levels in homes and workplaces. Promote education on how to remedy this issue through public service announcements and other programs.

Strategy 4: Work with the Montana Indoor Air Quality Program, tribal environmental departments, and other associated organizations to distribute educational materials on radon in the home. Promote the Radon Hotline: 1-800-546-0483.

Strategy 5: Promote indoor radon testing on sale of homes and in new construction where there is high radon potential; encourage distribution of EPA materials to realtors.

Objective IV.3: Improve public knowledge and awareness of common environmental carcinogens and promote methods to reduce exposure.

Baseline: To be determined.

Outcomes: Increased availability of educational opportunities, reduced exposure, and increased public awareness of environmental carcinogens.

Data sources: BRFSS; website visit counts; conference attendance; distribution of published materials.

Strategy 1: Design a tool to measure baseline public awareness of carcinogens, such as adding a question to BRFSS.

Strategy 2: Develop and maintain communication among agencies including the Environmental Public Health Tracking (EPHT), Department of Environmental Quality (DEQ), Department of Public Health and Human Services, Extension Service, Montana State University, University of Montana and others relative to issues pertaining to environmental carcinogens.

Strategy 3: Participate in and/or host conferences, seminars and other educational opportunities to further public awareness of environmental carcinogens that provide information on preventing exposure at home and in the workplace.

Strategy 4: Develop materials (written and/or web-based) discussing commonly encountered environmental carcinogens and provide information on preventing exposure.

Strategy 5: Support policies and programs designed to decrease exposure to environmental carcinogens.

Lifetime risk is the probability that someone, over the course of his or her lifetime, will develop cancer. In the United States, men have nearly a one in two lifetime risk of developing cancer; for women, the risk is a little more than one in three. (American Cancer Society 2003)

Prevention: What You Can Do

## Avoid:

- 1. Tobacco use
- 2. Secondhand smoke
- 3. Too much alcohol (one drink a day for women, two for men)

# Make healthy food choices:

- 1. Eat five or more servings of fruits and vegetables daily.
- 2. Maintain a low-fat diet.
- 3. Balance total calorie intake with calories expended through physical activity.

Maintain a healthy weight or body mass index: Ask your healthcare provider to measure this at least yearly.

# Be physically active:

- 1. Increase your moderate and vigorous activity per week.
- 2. Watch less than 2 hours of TV per day.

Protect your skin from sunlight, UV light exposure and tanning lights.

#### Discuss:

- 1. Cancer prevention and risk factors with your primary healthcare provider.
- 2. Your risk for cervical cancer with your healthcare provider.
- 3. Occupational exposure to carcinogens with your employer.

# Become knowledgeable:

- 1. About environmental carcinogens and your exposure to them.
- 2. Check your home-s radon level and take measures to decrease it if over 4pCi/L.

## Support:

- 1. Increasing the tobacco tax.
- 2. Policies reducing exposure to tobacco products and secondhand smoke.

### Advocate:

- 1. For increased funding for the Montana Tobacco Use Prevention Program.
- 2. For cancer prevention policies with your school board, workplace, state and local governments.

## A Montana Epidemic: Obesity and Overweight:

- 1. 57 percent of Montana adults are overweight or obese. (BRFSS 2002)
- 2. 17 percent of non-Hispanic white adults and 39 percent of American Indian adults in Montana are obese (BRFSS, 2002; Montana American Indian Behavioral Risk Survey, 2003).
- 3. The obesity rate among Montana adults increased by 115 percent between 1990 and 2002 (BRFSS, 1990, 2002).
- 4. 18 percent of Montana high school students are overweight or at risk of becoming overweight (YRBSS, 2001).

What does Aoverweight@ and Aobese@ mean? Overweight and obesity are labels for weight ranges greater than those generally considered healthy for a given height. The terms also identify weight ranges shown to increase the likelihood of certain diseases

and other health problems.

For adults, overweight and obesity ranges are determined by using weight and height to calculate a number called the Abody mass index@ (BMI). BMI is used because, for most people, it correlates with their amount of body fat. Although BMI correlates with the amount of body fat, it does not directly measure body fat. As a result, some people, such as athletes, may have a BMI that identifies them as overweight even though they do not have excess body fat.

Calculate BMI using the following formula: BMI = [(Weight in pounds) + (Height in inches) $^2$ ] x 703. For more information about BMI, visit <a href="https://www.cdc.gov/nccdphp/dnpa/bmi">www.cdc.gov/nccdphp/dnpa/bmi</a>.

Description of table: A person with a BMI of <18.5 is underweight. A person with a BMI of 18.5 -24.9 is normal. A person with a BMI of 25-29.9 is overweight. A person with a BMI of 30 or greater is obese. End of description.

Early Detection: Detecting cancers early through screening can lead to more effective treatment with fewer side effects.

A statewide program emphasizing early detection and prevention of cancer through screening and healthful living would reduce the rate of cancer in Montana. The use of screening tests to detect cancers in the early stages often leads to more effective, less expensive treatment with fewer side effects. Patients whose cancers are found early are more likely to survive than those whose cancers are not found until symptoms appear.

- 1. Screening mammograms every 12-33 months for women over age 40, followed by timely treatment when breast cancer is diagnosed, reduce the chances of dying from breast cancer.
- 2. Regular Pap smear tests followed by appropriate and timely treatment reduce death from cervical cancer. Women who have never been screened or who have not been screened in the past five years face a greater risk of developing invasive cervical cancer than their screened counterparts.
- 3. Colorectal cancer can be prevented and detected early through screening. The primary screening modalities include the fecal occult blood test, flexible sigmoidoscopy and colonoscopy. Precancerous polyps can be identified and may be removed during sigmoidoscopy or colonoscopy to prevent the development of cancer; cancers can also be detected at an early and curable stage.
- 4. Information should be provided to all men starting at the age of 50 about what is known and what is uncertain about the benefits and limitations of early detection and treatment of prostate cancer, so that they can make informed decisions. Prostate-specific antigen testing (PSA) and digital rectal examination (DRE) are the two primary methods used to screen for prostate cancer. PSA testing in combination with DRE is currently the best approach available for the early detection of prostate cancer.

Early Detection: We believe individuals will be more likely to access screening tests for cancer if urged to do so by their healthcare providers. Such discussions between provider and patient can result in partnerships for informed decision making relative to cancer risk, early detection and risk reduction. It is important for providers to discuss cancer risks and the tests available for early detection, as well as make referrals for screening tests. They are an invaluable resource for patients who need to make informed decisions in order to reduce their risk of cancer. Likewise, it is essential for individuals to be aware of cancer-screening guidelines so that they can initiate discussions with their healthcare providers.

Profile: Destiny Boyd has a strong family history of cancer. Her grandmother died of cancer, which scared Destiny=s mother enough that she went in at 35 for a colonoscopy. Just in time, as it turns out: doctors found a teardrop-sized cancer during the procedure. Destiny is very thankful that her mother has had follow-up treatment and is doing well. She=s also become a firm believer in the importance of routine cancer screenings. Destiny will be 25 this year B ten years younger than her mother was when her cancer was discovered. Her plans for the year include her first colonoscopy. ASo many things are preventable and colon cancer is one of them. People need to know that you just have to do this...for yourself and for your family.

Goal I: Promote compliance with cancer-screening guidelines.

Objective I.1: Increase compliance with the American Cancer Society (ACS) Cancer Detection Guidelines.

#### Baseline:

- 1. Breast: Women over 40 who have had a mammogram within the past two years: 71.9 percent
- 2. Cervical: Women over 18 who have had a PAP test in past three years: 86.1 percent
- 3. Colorectal: Adults over 50 who have ever received a sigmoidoscopy or colonoscopy exam: 52.6 percent
- 4. Prostate: To be determined

Outcomes: By 2011,

- 1. Breast: 75 percent of women over 40 will report having had a mammogram within the past two years.
- 2. Cervical: 90 percent of women over 18 will report having had a PAP test within the past three years (Healthy People 2010 goal: 90%)
- 3. Colorectal: 55 percent of adults over 50 will have had a sigmoidoscopy or colonoscopy exam (Healthy People 2010 goal: 50%).
- 4. Prostate: By 2008, identify the programs that offer education on informed decision-making for prostate cancer screening; identify the number of healthcare providers who offer informed decision making. By 2011, increase the number of providers and programs promoting informed decision-making on prostate cancer screening by a percentage to be determined.

Data source: Behavioral Risk Factor Surveillance System (BRFSS) 2004 and a healthcare provider survey.

Strategy 1: By 2008, identify the programs that offer education on informed decision-making for prostate cancer screening; identify the number of healthcare providers who offer informed decision making.

Strategy 2: Market the ACS Cancer Detection Guidelines to the healthcare provider community and the public.

Strategy 3: Provide the media with Center for Disease Control and Prevention (CDC) programs on cancer screening, including "Screen for Life".

Strategy 4: Inventory local community locations for all cancer-screening facilities and providers, including those serving Montana=s American Indian population. Promote a cancer type-specific community-level list to healthcare providers and the public; add to the "Cancer Resource Roster" on the Cancer Control web page.

Strategy 5: Analyze the inventory list for gaps in services and promote increased screening service capacity as needed.

Strategy 6: Promote and incorporate colorectal cancer information into workplace wellness programs and other community-based health-related education programs.

Strategy 7: Use existing or develop new culturally competent and medically appropriate materials on prostate cancer that healthcare providers and men can utilize to facilitate informed decision-making on prostate cancer screening.

Strategy 8: Increase the number of healthcare providers who discuss and recommend appropriate screening for breast, cervical, colorectal, and prostate cancers.

Strategy 9: Analyze available data on the scope of cancer screening among specific populations, including Medicaid and Medicare recipients. Implement strategies to rectify

any identified disparities. Determine the best strategies for improving access to screening.

Strategy 10: Review, revise and promote the clinical cancer screening protocols used for federally funded clinics, Indian Health Service facilities, and tribal health clinics.

For more information, visit <a href="www.cancer.org">www.cancer.org</a> and go to APrevention and Early Detection@ or go to <a href="http://progressreport.cancer.gov">http://progressreport.cancer.gov</a> and go to AEarly Detection.@

Objective I.2. Reduce barriers to cancer screening services.

Baseline: Barriers have not been identified.

Outcomes: Barriers are defined and corrective strategies implemented.

Data sources: Process evaluation results.

Strategy 1: Identify barriers to access, availability, and utilization of cancer-screening services; study and describe at the local level.

Strategy 2: Implement strategies to address identified barriers.

Early detection could substantially reduce the billions of dollars spent on cancer treatment each year. Not only does cancer screening save lives by detecting breast, cervical, and colorectal cancer early, it is also the first step in preventing some colorectal and cervical cancers from developing. Screening for colorectal cancer, as recommended by the U.S. Preventive Services Task Force, can reduce the number who die of this disease by at least 30 percent. Regular mammograms (every 1-2 years) can reduce the risk of dying of breast cancer for women age 40 and older by about 16 percent. Cervical cancer can be prevented by using the Pap test to detect precancerous lesions, which can be treated before cancer develops. Researchers in many countries found that rates of cervical cancer death dropped by 20 to 60 percent after screening programs began (CDC 2003).

Goal II: Healthcare providers will promote high-quality cancer screening and diagnostic services.

Objective II.1: Increase the accredited professional education available to Montana healthcare providers on state-of-the-art cancer screening, diagnosis, risk factors and prevention.

Baseline: To be determined.

Outcomes: By 2007, determine the baseline number of continuing education credits providers report that include cancer screening, diagnosis, and prevention. By 2011, increase the number of accredited courses on state-of-the-art cancer prevention, screening and diagnosis by a percentage to be determined.

Data sources: Healthcare provider survey.

Strategy 1: Conduct a healthcare provider survey to determine the accredited education courses available to Montana healthcare providers that include cancer prevention, screening, and diagnosis. Determine provider needs relative to cancer prevention, screening, and diagnosis.

Strategy 2: Develop a method to increase the number of accredited professional education opportunities available to Montana healthcare providers.

Strategy 3: Implement strategies to address the needs identified through the healthcare provider survey.

Your chances of developing colon cancer increase tremendously after age 50, but you are in the driver-s seat. Colon cancer starts with a growth that has not yet developed into cancer. Testing can help your doctor find and remove these growths before they become cancerous. Even if the test finds colon cancer, you have a much better chance if it-s found early.

Ensuring that people of all races, ethnicities, geographic locations, and socioeconomic levels have equal access to screening services will help achieve control of cancer in

#### Montana.

Goal III: Broaden coverage and utilization for cancer-screening services in Montana.

Objective III.1: Increase the proportion of insured Montanans screened for breast, cervical, colorectal, and prostate cancer.

### Baseline:

- 1. Breast: Insured women over 40 who have had a mammogram within the past two years: 75.5 percent
- 2. Cervical: Insured women over 18 who have had a Pap test in the past three years: 87.8 percent
- 3. Colorectal: Insured adults over 50 who have ever received a sigmoidoscopy or colonoscopy: 55.5 percent
- 4. Prostate: Insured men over 40 who have had a PSA test in the past two years: 57.3 percent

# Outcomes: By 2011:

- 1. Breast: 80 percent of insured women over 40 will have had a mammogram within the past two years
- 2. Cervical: 90 percent of insured women over 18 will have had a PAP test within the past three years (Healthy People 2010 goal: 90 percent)
- 3. Colorectal: 60 percent of insured adults over 50 will have received a sigmoidoscopy or colonoscopy,
- 4. Prostate: 60 percent of insured men over 40 will have had a PSA test within the past two years.

Data source: BRFSS 2002; insured respondents.

Strategy 1: Identify additional data sources and analyze baseline data needs.

Strategy 2: Collect and evaluate utilization data for major health plans in Montana; analyze utilization and coverage gaps.

Strategy 3: Work with healthcare plans to promote and increase the utilization of cancer screening and diagnostic services. Monitor, promote, and protect existing private and public health insurance coverage for cancer screening.

Strategy 4: Address known underutilization (e.g., colorectal and breast in Medicare) and promote culturally competent patient education.

Profile: Five generations of a Crow family come together for Messengers for Health.

The best method for delivering female health education on the Crow Indian Reservation is through women respected by the Tribe. Messengers for Health, a four-year-old program on the Apsaalooke (Crow) Reservation, successfully uses this technique. The program is based at Montana State University and funded by the American Cancer Society.

Alma Knows His Gun McCormick, Messengers for Health Project Coordinator, speaks the Crow language as fluently as she speaks English. She needs both in her work with 32 Crow women who have been trained to provide grassroots cancer outreach for Messengers for Health. Crow women have learned about health and life in familiar settings from tribeswomen they trust and respect. The Messengers for Health outreach workers are dispensing information on cervical cancer in the traditional way: by visiting with friends and relatives. AWe have been able to encourage women for health (issues) and for other things, McCormick said. AWe are working for a good purpose. Women here are beginning to feel empowered, comfortable enough even to schedule their own (cancer) screening appointments. They are beginning to know the importance of a Pap test. We are overcoming barriers.

That is important because Northern Plains Indians have a statistically higher mortality rate from cervical cancer than their White neighbors. Screenings are vital because most women who develop cervical cancer do not have symptoms. When a Pap test reveals cervical cancer early, close to 100 percent of women survive.

The first 25 Messengers, recruited in July 2002, had all been identified as women others naturally sought out for advice. Initially, their work focused on cervical cancer, but from the beginning, the program became a clearinghouse for all manner of health-related information.

AThis program gives women information on many health topics and sends the message that it's important for women to take care of themselves so that we can be there for our families, McCormick said. (Gratefully adapted from AMessengers for Health Uses Traditional Crow Relationships to Teach About Contemporary Health by Carol Schmidt. MSU News, 6/30/05.

Reducing Mortality Through Screening and Early Detection: Many deaths from breast and cervical cancers could be avoided by increasing cancer screening rates with mammography and Papanicolaou (Pap) tests. Deaths from breast and cervical cancer occur disproportionately among women who are uninsured or underinsured.

Timely mammography screening among women aged 40 years or older could prevent approximately 16 percent of all deaths from breast cancer. Mammography is the best available method to detect breast cancer in its earliest, most treatable stage. an average of one to three years before a woman can feel a lump. Women aged 40 years or older should have a screening mammogram every 12 to 24 months. Except for skin cancer, breast cancer is the most commonly diagnosed cancer among women in the United States, and second to lung cancer as the leading cause of cancer-related death among women. If detected early, the U.S. five-year survival rate for localized breast cancer is 97 percent.

Cervical cancer screening using the Pap test detects cancer as well as precancerous

lesions. Women should begin getting a Pap test within three years of onset of sexual activity or age 21, whichever comes first. Pap tests can find cervical cancer at an early stage when it is most curable, and can actually prevent the disease if precancerous lesions found during the test are treated. The incidence of invasive cervical cancer has decreased significantly over the last 40 years, in large part because of screening for, and treatment of, precancerous cervical lesions. Routine screening for cervical cancer can prevent the disease.

For more information, visit the Center for Disease Control and Prevention (CDC): <a href="https://www.cdc.gov/cancer/nbccedp">www.cdc.gov/cancer/nbccedp</a> .

American Cancer Society Guidelines:

The following cancer screening guidelines are primarily recommended for people at average risk for cancer who do not have any specific symptoms. People who are at increased risk for certain cancers may need to follow a different screening schedule recommended by their primary healthcare provider.

Cancer-Related Checkup: A cancer-related checkup should include health counseling and depending on age, might include examinations for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries, as well as for some non-malignant diseases.

Breast Cancer: The American Cancer Society recommends yearly mammograms starting at age 40, which continue for as long as a woman is in good health. Clinical breast exams (CBE) should be part of periodic health exams, about every three years for women in their 20s and 30s, and annually for women age 40 and over. Women should report breast changes promptly to their healthcare providers.

Colon and Rectal Cancer: Beginning at age 50, men and women at average risk for developing colorectal cancer should follow one of the following testing schedules:

- 1. yearly fecal occult blood test (FOBT) or fecal immunochemical test (FIT);
- 2. flexible sigmoidoscopy every five years;
- 3. yearly FOBT or FIT plus flexible sigmoidoscopy every five years;
- 4. double-contrast barium enema every five years;
- 5. colonoscopy every ten years.

All positive tests should be followed up with colonoscopy. People should begin colorectal cancer screening earlier and/or undergo screening more often if they have any of the following colorectal cancer risk factors:

- 1. a personal history of colorectal cancer or adenomatous polyps;
- 2. a strong family history of colorectal cancer or polyps;
- 3. a personal history of chronic inflammatory bowel disease;
- 4. a family history of hereditary colorectal cancer syndrome.

The costs of treating early-stage colorectal cancer are approximately 1/4 the cost of treating this cancer at a later stage, with cost savings of between \$24,000 and \$34,000 per person. B <a href="https://www.gastro.org/pubPolicy/issueBriefs/urges.html">www.gastro.org/pubPolicy/issueBriefs/urges.html</a>.

Cervical Cancer: All women should begin cervical cancer screening about three years after they begin having vaginal intercourse, but no later than 21 years of age. Screening should be done annually with the standard Pap test or every two years with the liquid-based Pap test. Beginning at age 30, women who have had three normal Pap test results in a row may get screened every two to three years. Women who have risk factors including diethylstilbestrol (DES) exposure before birth, Human Immunodeficiency Virus (HIV) infection, or a weakened immune system should continue to be screened annually.

Endometrial (Uterine) Cancer: Women should be informed about the risks and symptoms of endometrial cancer, and are strongly encouraged to report any unexpected bleeding or spotting to their doctors. For women with, or at high risk of, hereditary nonpolyposis colon cancer (HNPCC), annual screening for endometrial cancer with endometrial biopsy should be offered beginning at age 35.

Prostate Cancer: Both the prostate-specific antigen (PSA) blood test and digital rectal examination (DRE) should be offered annually, beginning at age 50, to men who have at least a ten-year life expectancy. Men at high risk, including those with a strong family history of prostate cancer diagnosed at an early age, should begin testing at age 45. Men at even higher risk, due to multiple first-degree relatives affected at an early age, could begin testing at age 40. Depending on the results of this initial test, no further testing might be needed until age 45.

For more information, visit the American Cancer Society at <a href="www.cancer.org">www.cancer.org</a>.

Objective III.2: Increase the cancer-screening services available to under-insured and uninsured Montanans, as consistent with nationally accepted screening guidelines.

### Baseline:

- 1. Breast: Uninsured women over 40 who have had a mammogram within the past two years: 47.2 percent.
- 2. Cervical: Uninsured women over 18 who have had a Pap test in the past three years: 79.2 percent.
- 3. Colorectal: Uninsured adults over 50 who have received a sigmoidoscopy or colonoscopy: 28 percent.
- 4. Prostate: Uninsured men over 40 who have had a PSA test in the past two years: 33.3 percent.
- 5. No list of low-cost services available.

Outcomes: By 2011,

- 1. Breast: 70 percent of uninsured women over 40 will have had a mammogram within the past two years (Healthy People 2010 goal: 70 percent).
- 2. Cervical: 90 percent of uninsured women over 18 will have had a PAP test within the past three years (Healthy People 2010 goal: 90 percent).
- 3. Colorectal: 50 percent of uninsured adults over 50 who have ever received a sigmoidoscopy or colonoscopy (Healthy People 2010 goal: 50 percent).
- 4. Prostate: 50 percent of uninsured men over 40 will have had a PSA test within the past two years.
- 5. List of free or low-cost cancer-screening services will be made available to the public and healthcare providers.

Data source: BRFSS 2004; uninsured respondents; process evaluation results.

Strategy 1: Identify additional data sources and analyze baseline data needs.

Strategy 2: Analyze Montana policies and laws on cancer-screening coverage; implement strategies to improve identified gaps.

Strategy 3: Support legislative efforts and policies to broaden patients= private and public health plan coverage for cancer screening; broaden coverage for cancer screening among low-income, under- and uninsured Montanans.

Strategy 4: Work with the Montana State Planning Grant and similar organizations to increase Montanans=insurance coverage for cancer screening and diagnosis.

Strategy 5: Collect data to determine cancer-screening coverage included in insurance plans; implement strategies to address gaps and disparities. Encourage insurance providers to provide for screening services based on evidence-based screening quidelines.

Strategy 6: Identify, create and disseminate a list of agencies that provide funds and/or services for breast, cervical, colorectal, and prostate cancer screening. Add this resource list to the "Cancer Resource Roster" on the Cancer Control web page. Strategy 7: Support funding for:

A. Indian Health Services to cover cancer screening needs.

- B. Ongoing implementation of the Montana Breast and Cervical Health Program.
- C. Title X (Family Planning) activities in Montana that provide cervical cancer screening and clinical diagnostic services.

Strategy 8: Support efforts to ensure healthcare providers and their staffs receive ongoing education about low- or no-cost cancer screening resources.

Strategy 9: Support incentives for individuals and small businesses to purchase health insurance that covers cancer screening.

Early Detection: What You Can Do:

## Be proactive:

- 1. Follow the American Cancer Society-s Cancer Detection Guidelines.
- 2. Discuss screening for breast, cervical, colorectal, and prostate cancer that may be appropriate for you and your family with your healthcare provider.
- 3. Encourage your friends and family to get screened for cancer early detection.

Support policies: Encourage health plan coverage for cancer screening.

Be smart: If you=re 50 or older, it's time to get tested for cancer. In Montana, 93 percent of all people diagnosed with colon cancer are 50+ and 81 percent of women diagnosed with breast cancer are 50+ (Montana Central Tumor Registry 1999-2003).

Be informed: Know your cancer risk and know the cancer screening recommendations appropriate for you.

Screening for Skin Cancer: Most melanomas of the skin can be seen by the naked eye, and skin cancer can be cured if the tumor is found before it spreads deeper. Skin cancer screening during regular clinical visits involves a two or three minute visual inspection of the entire body. The American College of Preventive Medicine recommends periodic total cutaneous examinations for populations at high risk, which include those with personal or family histories of melanoma, more than 50 moles, dysplastic nevi, a fair completion, a weakened immune system, or a history of blistering sunburns, especially as a child or teenager. Increased exposure to ultraviolet radiation from the sun or artificial sources increases risk.

Check your skin once a month. The A-B-C-D-E Rule can distinguish a normal mole from a melanoma. Notify your doctor if you notice of these signs.

A is for asymmetry: One half of a mole or birthmark does not match the other.

B is for border: Edges are irregular, ragged, notched, or blurred.

C is for color: The color is not the same all over and may include shades of brown or black, or may have patches of red, white or blue.

D is for diameter: The spot is larger than 6 millimeters across (about the size of a pencil eraser) or is growing larger.

E is for evolving: Lesions significantly change in size, shape, symptoms, surface, or shades. (Adapted from <a href="https://www.cancer.org">www.cancer.org</a> and <a href="https://www.acpm.org/skincare.htm">www.acpm.org/skincare.htm</a>)

Screening for Oral Cancer: Many oral cancers can be found early, during routine screening examinations or by self-examination. Many doctors and dentists recommend that you look at your mouth in a mirror every month to check for any symptoms listed below. If these signs last more than two weeks, contact your doctor or dentist:

- 1. lip or mouth sore that doesn-t heal within two weeks.
- 2. lump in the mouth.
- 3. lump elsewhere, such as the face, jawbone or neck.
- 4. white/red patch on the gums, tongue or mouth lining.
- 5. unusual bleeding or pain; difficulty chewing or swallowing (Adapted from <a href="https://www.cancer.org">www.cancer.org</a>)

Description of table: Montana-s Progress Toward Healthy People 2010 Goals. In 2004, 86.1% of Montana women aged 18 and older had had a Pap smear in the last three

years. The Healthy People 2010 objective is 90%. 71.9% of Montana women aged 40 and older had had a mammogram in the last two years. The Healthy People 2010 objective is 70%. 52.6% of Montanans aged 50 and older had ever had a sigmoidoscopy or colonoscopy. The Healthy People 2010 objective is 50%. End of description.

Treatment: We envision comprehensive cancer treatment that meets national standards B available to, and accessible by, all Montanans.

Cancer is a complex group of diseases. To further complicate matters, different cancers behave differently and respond to different treatments. Treatment choices depend upon the type and stage of cancer as well as a variety of individual factors that include age, health, cultural and personal preferences. Care is comprised of various services, resources and technology.

On average, 4,495 new cancer diagnoses are reported annually in Montana and 4,022 cases of cancer are treated annually. (Montana Central Tumor 5-year averages, 1999-2003.) To effectively improve cancer treatment outcomes, state-of-the-art care must be available, accessible, affordable, and utilized. It is crucial to integrate, coordinate and maximize treatment, services and resources.

While good cancer treatment can be available at the local level, Commission on Cancer (CoC) approval ensures the quality of cancer care through adherence to national standards, multidisciplinary consultation and quality assessments. All sizes of facilities may be approved as the standards are categorized based on the number of cancer patients treated. As of January 2005, four of Montanas medical facilities were CoC approved. In 2003, the most recent year for which a complete set of data are available, 36 percent of Montanans with cancer were treated in CoC approved centers. Nationally, 80 percent of cancer patients are treated in CoC approved facilities.

- 1. Clinical practice guidelines serve as a guide for doctors and outline appropriate methods of cancer treatment, rehabilitation and follow-up care.
- 2. A system of community health advisors, patient navigation tools and Quality of Life Resource Centers would improve use of the complex cancer healthcare system, guide the patient and family, decrease stress, and improve communication.
- 3. Efficient use of treatment services requires that evidence-based information be available to healthcare providers and the public.

Availability: Montana is the fourth largest state in terms of land mass, encompassing 147,046 square miles, and has just over 900,000 residents. This equates to about six people per square mile, making Montana one of the last remaining frontier states. Lengthy distances between population centers, coupled with a small population, become obstacles to availability, capacity and consistent state-of-the-art treatment.

Accessibility: Access to state-of-the art cancer treatment can be limited by a variety of personal, geographical, and cultural barriers. This may include lack of insurance, cost

of care, location, lack of transportation, extraneous costs including travel, child care, as well as other cultural and physical barriers. Cancer patients should have access to all forms of therapy from which they can benefit.

Affordability: Cost may be the biggest barrier to accessibility and optimum cancer treatment. For the 19 percent of Montanans who lack health insurance, cost is overwhelming. Even those who have health insurance may find that their carrier doesn-t provide complete coverage.

Utilization: In order to fully utilize state-of-the-art services, cancer patients and their families must be aware of available services. Maximizing utilization means empowering patients and their families by ensuring that they know and understand their options.

# First Steps:

- 1. Identify gaps in the availability and types of cancer treatment services; and;
- 2. Identify barriers to accessibility and utilization of cancer care services, which might include cost, geographic location, cultural factors, uneven distribution of resources, or care choices that lack standardization.

The National Comprehensive Cancer Network (NCCN) is an alliance working to develop treatment guidelines as tools to guide decision-making in cancer management. The Commission on Cancer (CoC) is a consortium of professional organizations dedicated to reducing the morbidity and mortality of cancer through education, standard-setting, and monitoring the quality of care. Membership is comprised of 100+representatives of the American College of Surgeons (ACoS) and the 39 national affiliated professional organizations.

The Commission sets standards for quality, multidisciplinary cancer care; surveys hospitals; collects quality data with which to measure treatment patterns and outcomes; evaluates hospital provider performance; and develops educational interventions to improve cancer care outcomes at national and local levels.

Goal I: Ensure prevailing standards of care for all cancer patients.

Objective I.1: Increase the percentage of cancer patients given care consistent with national treatment standards.

Baseline: Thirty-six percent of cancer patients were treated by three CoC-approved programs in 2003.

Outcomes: By 2007, determine the percentage of patients whose treatment was consistent with national standards, but who were not treated in CoC-approved programs. By 2011,

- 1. Define treatment barriers.
- 2. Define and promote treatment standards and resources.

- 3. Increase the number of CoC-approved programs in Montana to six.
- 4. Increase the number of patients treated at CoC-approved cancer treatment centers by 25 percent.

Data sources: Montana Central Tumor Registry (MCTR) 2002; CoC 2005; provider survey.

Strategy 1: Determine the percentage of patients whose treatment was consistent with national standards, but who were not treated in CoC-approved programs.

Strategy 2: Promote visibility of CoC-approved programs by citing accredited programs in cancer-treatment related materials and promotions.

Strategy 3: Encourage unaccredited centers treating cancers to move to CoC approval status appropriate to their size.

Strategy 4: Support ongoing accreditation of CoC- approved programs. Strategy 5:

A. Educate cancer patients about resources available, treatment options, national treatment standards, rehabilitation and follow-up guidelines in a cancer-specific format.

B. Educate health care providers about the resources available and promote national cancer treatment standards and evidence-based practices as user-friendly tools that are site and stage specific.

Strategy 6: Identify cancer patients= barriers to engaging in treatment, rehabilitation and follow-up consistent with national standards. Analyze disparities across population groups (e.g. racial, disability status, geographic, economic). Design and implement strategies to assist patients in overcoming these barriers.

Strategy 7: Promote accredited, professional, cancer-related education sessions on evidence-based best practices, national standards, guidelines, cost-effective treatment and follow-up care.

Strategy 8: Support enhanced telemedicine capacity.

Strategy 9: Promote resources and coordination for follow-up care in frontier and American Indian reservation communities.

Objective I.2: Enhance childhood cancer oncology services in Montana.

Baseline: Data, analysis, and protocols are not available.

Outcomes: By 2008,

- 1. Define need for childhood oncology services.
- 2. Quantify and define service gaps and disparities.
- 3. Create, institute and promote communication protocols.

Data sources: Process evaluation results.

Strategy 1: Establish a committee to delineate and analyze data: A. to determine the need for a pediatric oncologist to provide full- or part-time consultation to childhood cancer patients and their families. B. to determine disparities and gaps in childhood cancer services.

Strategy 2: If need is determined, strategize and implement enhancements to childhood cancer services.

Strategy 3: Establish and promote protocols for communication:

A. among local, regional and tertiary childhood cancer treatment centers; and B. among medical service providers and parents.

Profile: Rylie was just three when she started complaining of a headache. When it didn-t let up after a few days, Rylie-s mother, Kim, took her to the pediatrician, who attributed the toddler-s symptoms to a virus. That was in early June 2002. Four days later, Rylie wasn-t better, and they went back in the pediatrician-s office. Though he prescribed antibiotics, Rylie remained listless, and began running a low-grade temperature. After a few more days, Kim took Rylie back for the third time. This time, the pediatrician ordered some tests. Kim and Rylie hadn-t been home for two hours when the doctor called. All need you and your husband to come back in, right now.@

The doctor was pretty certain that Rylie had leukemia, but said that they=d have to take her to the pediatric oncology center at the Denver Children=s Hospital for confirmation. The only option they could afford was to drive her there, so Kim and her mother left the next day, with Rylie in the back seat. The diagnosis came back June 25, and Rylie started intravenous chemotherapy immediately. She stayed in the hospital for a week. After the initial round of chemotherapy, her test results were good. Even so, 17 months of intense chemotherapy followed. Every four months, Rylie and Kim would travel to Denver, then return to Montana for follow-up care.

They thought they were out of the woods, but in November 2003, Rylie started complaining of headaches again. The cancer was now in Rylie-s central nervous system, and her best chance lay in an unrelated umbilical cord blood transplant. The Fairview University Medical Center was a pioneer in the field; by then they had done over 6,000 cord blood transplants. March 1, Rylie, Kim, Rylie-s dad, Chris, and her brother TY, arrived in Minneapolis. Rylie went through two months of intensive chemotherapy, a time that Kim remembers as the worst of all. The transplant itself was uneventful, and Rylie did remarkably well. She was up and playing almost immediately.

The good news? Rylie-s last day of medication was July 26, 2005, two days before her sixth birthday. AAt first I thought we didn-t need other people, that we could handle this ourselves. That just wasn-t true. Throughout Rylie-s illness, we-ve received a lot of emotional and financial support from others. The financial support, especially, was hard to accept, but ultimately it taught me that it-s okay to accept help. Everyone was so good to us. It seemed that everyone who heard about Rylie wanted to help. If not for the generosity people showed us, we would be telling a completely different story today. (Kim, mother of Rylie, a 6-year-old cancer survivor.)

Montana children diagnosed with cancer are referred out-of-state to regional cancer centers for initial treatment. Travel becomes a major obstacle for families.

AResidents of poorer counties, irrespective of race, have higher death rates from cancer. Disparities are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role. (Harold Freeman, M.D.)

Goal II: Promote utilization of appropriate cancer services for childhood cancer patients and their families.

Objective II.1: Make a list of short-notice travel resources for children diagnosed with cancer and their families.

Baseline: No resource list is available for distribution.

Outcomes: By 2008, make a travel resource list available.

Data sources: Process evaluation.

Strategy 1: Compile a list of current resources available for transportation to regional cancer centers, as well as resources providing for in. and out-of-state travel expenses and destination housing options.

Strategy 2: Create and disseminate a travel resource list for newly diagnosed pediatric cancer patients and add to the "Cancer Resource Roster" on the Cancer Control web page.

Strategy 3: Identify and improve funding available for transportation and housing for childhood cancer patients and their families.

Goal III: Assess and improve availability, accessibility, and timely utilization of cancer treatment services for all populations.

Objective III.1: Analyze and improve cancer treatment services by geography, ethnicity, socioeconomic level, age, disability, and insurance status.

Baseline: No clinically-based analyses have been identified.

Outcomes: By 2008,

- 1. Identify data resources for use in analysis.
- 2. Analyze and make recommendations for addressing identified barriers, gaps, and disparities.
- 3. Identify public policies that present obstacles to equitable treatment.
- 4. Make recommendations for appropriate remediation.

Data sources: Process evaluation results.

Strategy 1: Identify existing cancer data and analyze for barriers and disparities to availability, accessibility, and utilization by specific factors (e.g., incidence, mortality,

outcomes, cost, insurance coverage, readmission rates, treatment choices, types of treatment, resources, and efficiency). If data are unavailable, identify ways to meet data needs.

Strategy 2: Analyze public policy for barriers to treatment.

Strategy 3: Compare Montana-s data with national trends to identify significant variations.

Strategy 4. Develop strategies for implementation that will address identified disparities and barriers, and fill service gaps.

Objective III.2: Reduce economic barriers to quality care for cancer patients.

Baseline: 4.5 percent of Montana cancer patients are coded Ano insurance in the primary payer field of the MCTR (2001-2002).

Outcomes: By 2011,

A. reduce the number of Montana cancer patients coded as no insurance to 4 percent; and

B. ensure that a wide range of assistance is available for the under- and uninsured.

Data sources: MCTR; process evaluation results.

Strategy 1: Support policies and legislation designed to broaden insurance coverage for diagnostic and treatment services for low income, under- and uninsured cancer patients. Strategy 2: Support incentives that allow individuals and small businesses to purchase health insurance.

Strategy 3: Support efforts to ensure healthcare providers and staff receive ongoing education regarding low- or no-cost treatment resources.

Strategy 4: Collect the data necessary to:

A. analyze insurance coverage for cancer treatment.

B. determine the scope and reasons for lack/delay of treatment among diagnosed cancer patients.

C. identify and implement strategies designed to reduce economic barriers and inequities.

Strategy 5: Support continued funding for the Breast and Cervical Cancer Treatment Program, the Montana Comprehensive Health Association, community health centers, and cancer treatment through the Indian Health Service.

Strategy 6: Support Medicaid reimbursement to healthcare providers at economically viable levels.

Strategy 7: Support expansion of Medicaid and Children-s Health Insurance Program (CHIP) eligibility and benefits to:

A. provide adequate coverage to uninsured cancer patients and their families.

B. reduce any identified health disparities among racial and ethnic groups, poor, and medically underserved populations.

C. improve access to cancer care for medically underserved populations.

D. increase Medicaid and CHIP benefit utilization for adults and children with cancer

Strategy 8: Work with the Montana State Planning Grant or similar organization on under- and uninsured cancer treatment issues.

Note: Women screened through the Montana Breast and Cervical Health Program may also be eligible for treatment benefits through the Montana Breast and Cervical Cancer Treatment Program.

Objective III.3: Increase the number of healthcare providers offering their patients help navigating the cancer care system.

Baseline: A comprehensive cancer treatment resource list is unavailable; there are no American Cancer Society (ACS) Resource Centers in Montana.

Outcomes: By 2008, create a statewide cancer treatment resource list and determine the number of cancer treatment centers and healthcare providers offering patients access to community health advisor navigator programs, self-navigation guides, or resource directories.

By 2011,

A. implement Cancer Resource Centers in five locations; and

B. increase by 20 percent the number of cancer treatment centers and providers that facilitate access to community health advisor navigator programs, self-navigation guides or resource directories.

Data sources: Process evaluation results; provider survey.

Strategy 1: By 2008, determine the baseline percentage of cancer treatment centers, tribal health systems, and providers that facilitate access to navigation guides or resource directories for cancer patients and families.

Strategy 2: Compile a list of cancer-related treatment resources in Montana, organized by geography and update annually. Make the list available to cancer treatment centers, providers, and the interested public.

Strategy 3: Add the treatment resource list to the "Cancer Resource Roster" on the Cancer Control webpage.

Strategy 4: Analyze resource gaps in availability and barriers to access and utilization; design strategies to improve resource distribution and utilization.

Strategy 5: Promote establishment of evidenced-based community health advisors or navigator programs; promote utilization of the programs starting at the time of diagnosis. Encourage cancer treatment center navigator programs to practice outreach to the frontier communities in their referral areas.

Strategy 6: Encourage navigator and resource staff training in clinical and insurance systems, national standards and trends, cost-effective measures, resources and services.

Strategy 7: Investigate funding to start an ACS Navigator Program in Montana.

Strategy 8: Promote establishment of ACS Cancer Resource Centers; start with cancer treatment centers and expand outreach to referral communities.

Strategy 9: Sponsor distribution of patient self-navigation programs. Consider promoting a cancer-specific checklist to improve cohesion of clinical services.

Montana by the Numbers (2000 Census):

- 1. Montana is a racially homogeneous state: 92.2 percent of the population is White. The largest minority is American Indian, who comprise approximately 7.4 percent of the population.
- 2. 16.9 percent of the population between the ages of 21.64 and 39.6 percent of the population aged 65+ have a disability.
- 3. 14.6 percent of the population overall is living in poverty.
- 4. The annual median household income is \$33,024. The annual per capita income is \$17.151.
- 5. Of Montana=s 56 counties, 45 qualify for Afrontier@ status because they have six or fewer people per square mile.

Goal IV: Promote optimum patient/provider communication to improve cancer survivors= experiences as healthcare consumers.

Objective IV.1: Increase healthcare providers= communication skills with cancer survivors and their families regarding the illness, prognosis, treatment, and follow-up options.

Baseline: The number of accredited education courses currently (2006) available to physicians, nurses, pharmacists and other healthcare professionals that address communication with cancer patients and their loved ones; the number of courses on this topic currently available to and required of healthcare students.

#### Outcomes:

- 1. By 2008, determine the baseline.
- 2. By 2010, increase by a percentage to be determined the number of accredited education courses for health care professionals and the number of required courses available to healthcare students on communicating with cancer patients and their loved ones.

Data sources: To be determined.

Strategy 1: Determine the baseline number of accredited education courses and required courses available to healthcare professionals and students on the topic of culturally appropriate communication with cancer patients and families.

Strategy 2: Work with appropriate entities to increase the number of courses available in Montana so that each healthcare provider who comes in contact with cancer survivors has received training on the topic at least once every five years.

Strategy 3: Explore incentives to encourage healthcare providers to increase their knowledge and communication skills.

Patients who fully understand the treatment program experience greater satisfaction with their care, and are more likely to complete treatment despite the inevitable side effects.

Objective IV.2: Review, develop, and promote resources for improving patient-provider communication.

Baseline: Resources currently available to patients on communication with providers.

Outcomes: By 2008, delineate the resources available to patients on communication with providers. By 2010, make a communications tool available to all cancer patients

Data sources: Process evaluation results.

Strategy 1: By 2008, determine what resources are available to patients on communication with providers.

Strategy 2: Add the patient/provider communication resource list to the "Cancer Control Resource Roster" on the Cancer Control website and promote it to the public.

Strategy 3: Define the common barriers to patient/provider communication.

Strategy 4: Identify programs or services to assist in overcoming barriers to patient/provider communication. If no effective program exists, develop an effective, comprehensive, culturally competent tool to help patients communicate with their providers.

Treatment: What You Can Do:

Be proactive: If you or a family member is diagnosed with cancer, become familiar with treatment options as well as national treatment, rehabilitation and follow-up guidelines for that cancer. Ask about appropriate lower-cost treatment choices.

Educate yourself: Use the community health advisor, navigator tools, resource centers and rosters available for cancer patients.

### Encourage:

- 1. your healthcare providers to participate in state-of-the-art educational opportunities on cancer diagnosis, treatment and evidence-based cost-effective care.
- 2. your local cancer treatment center to pursue size-appropriate Commission on Cancer approval.

#### Support:

- 1. funding to assist the families of childhood cancer patients with travel;
- 2. participation in Comprehensive Cancer Control projects in your community; and
- 3. policies that improve access to quality care for low income and uninsured Montanans.

Utilize: the resources available on effective communication to interact with your healthcare provider.

Profile: Rita McDonald is a colon cancer survivor. All could have been better informed, eshe says. All wasnet told that I should get a screening colonoscopy. I was totally in the dark. Thates why ites so important to me to get the word out. I want to make a difference B no one should have to go through what I have and the cancer I had is almost 100 percent preventable.

Rita was experiencing diarrhea and other symptoms, but had written it off to something she=d encountered on a recent vacation. When she went in to see her doctor about it, though, she was immediately sent in for a colonoscopy. Within a week, she was in surgery. Unfortunately, the cancer had already moved into Rita=s lymphatic system, making it much more difficult to treat. Rita says that she is thankful that she had symptoms. Colon cancer is often called the Asilent killer@because there are often no symptoms until late in the disease.

After her surgery, Rita remembers lying in the hospital thinking that she would make sure everyone she loved knew about this. She promised herself that she would do whatever she could to see that this didn-t happen to any of her family or friends. With Rita-s encouragement, her sister and sister-in-law both had colonoscopies that July. As it turns out, her sister-in-law had colon cancer, and her sister had polyps, which can develop into colon cancer if not removed. Both were caught in time. Rita was lucky, too: January 2005 marked three years of being cancer free. AThis has been a really, really long ordeal. I just want so much to make an impact on people so that they know they don-t have to go through what I-m going through. People need to understand that colon cancer is preventable. (Rita McDonald.)

Quality of Life and Survivorship:

Quality of Life: The individuals definition of what is acceptable physically, psychologically, and spiritually.

Quality of Life is a standard throughout the cancer care continuum - from diagnosis to remission, cure, or end of life. It includes active treatment, survivorship, rehabilitation, palliative care, and hospice. Palliative care identifies and addresses the physical, psychological, spiritual, and practical burdens of illness. It is offered by an interdisciplinary team that includes medical professionals, social services, spiritual advisors, and others. All are focused on the relief of suffering and on supporting the best possible quality of life for patients facing life-threatening illness and their families.

Though research indicates that cancer patients= pain and other symptoms often are not well controlled, good symptom management can contribute to improved quality and length of life. Medical literature suggests that patients and families may have better outcomes if they are able to understand and direct their care. In addition, many patients

express the need to maintain control over their care and feel that it improves their quality of life and survivorship. Many cancer patients rely on spiritual or religious beliefs and practices to help them cope with their diseases. Some patients may want their doctors and caregivers to acknowledge their spiritual concerns, not only for end-of-life issues but also during treatment. According to the Institute of Medicine, quality end-of-life care should include pain management, psychosocial support, and timely referral to hospice.

Increasingly, patients are using complementary and integrative medicine, which support and are used in conjunction with traditional, evidence-based treatment. Complementary therapies might include such activities as acupuncture, massage, meditation, music therapy or biofeedback. Cancer patients should have access to all forms of therapy from which they can benefit. Integrative medicine is a total approach to medicine that involves mind, body, and spirit. For example, relaxation might be used as a way to reduce stress during chemotherapy.

Childhood cancer brings with it a host of issues that affect the entire family. Having cancer can bring physical, emotional, and cognitive changes that affect a child's ability to perform. Even so, returning to normal routines as quickly as possible can provide a sense of purpose and hope to the family.

Nationally, the number of cancer survivors tripled between 1971 and 1999. There were 9.8 million survivors in 2001.

Stages of Grief: Elizabeth Kubler-Ross originally defined the stages a person goes through after learning of a serious illness, suffering a loss, or a major life change.

- 1. Denial
- 2. Anger
- 3. Bargaining
- 4. Depression
- 5. Acceptance

Montana has palliative care programs in most major cities. Two meetings have been held to initiate communication and facilitate cooperation among these programs.

Goal I: Promote quality of life for cancer patients.

Objective I.1: Increase the percentage of hospitals that offer pain management programs for cancer patients.

Baseline: Twenty-four percent of Montana hospitals reported pain management programs ("Last Acts: Means to a Better End. A Report on Dying in America Today" 2002. Montana)

Outcomes: By 2011, increase the percentage of hospitals offering cancer pain

## management programs to 50 percent

Data sources: Hospital survey

Strategy 1: Determine the percentage of hospitals offering pain management programs. Strategy 2: Support the cancer-related activities of the "Task Force on Pain and Symptom Management" recognized by the Montana Legislature. Consider the task force's recommendations on pain and symptom management interventions, use of complementary medicine, the needs of the medically underserved, drug repositories, and end-of-life cancer pain treatment. Consider the Task Force-s analysis of state statutes.

Strategy 3: Promote pain management standards and develop an implementation plan for increasing the number of cancer pain management programs.

Strategy 4: Educate the healthcare provider and patient communities about standards related to cancer pain management.

Pain Management: There are disparities in access to effective pain management for special populations, particularly racial minorities, children and the elderly. For example, research indicates that nearly one-third of children=s cancer centers in North America did not use general anesthesia or deep sedation for the majority of bone marrow procedures, and more than 25 percent used either nothing or topical anesthesia ("Pain Information for Professionals". American Cancer Society: www.cancer.org).

Palliative Care: Palliative care and symptom management is medical care that lessens pain or the effects from treatment of a disease, such as cancer. It helps to make patients more comfortable at every stage of illness. It is also referred to as supportive care.

Palliative Care Guidelines: There are now practice guidelines for quality palliative care established through the "National Consensus Project for Quality Palliative Care". These will set the standard for palliative care programs across the nation. The guidelines describe core precepts for clinical palliative care programs.

Aspects of Care are psychological and psychiatric, physical, social and cultural, spiritual, religious and existential. Structure and Processes include care of the imminently dying patient, and ethical and legal issues. Adapted from: <a href="https://www.nationalconsensusproject.org">www.nationalconsensusproject.org</a>

Objective I.2: Increase the percentage of hospitals offering palliative care programs that address cancer and treatment symptom management.

Baseline: Sixteen percent of Montana hospitals reported palliative care programs ("Last Acts: Means to a Better End. A Report on Dying in America Today" 2002. Montana)

Outcomes: By 2011, increase the percentage of hospitals reporting palliative care and

symptom management programs for cancer patients to 30 percent

Data sources: Hospital survey

Strategy 1: Determine the percentage offering palliative care and symptom management programs.

Strategy 2: Ensure that cancer survivors across Montana have access to palliative care, symptom management, and hospice programs.

Strategy 3: Promote national palliative care standards and develop an implementation plan to increase palliative care programs that address symptoms during cancer treatment for cancer survivors of all ages.

Strategy 4: Encourage palliative care programs to include routine recommended order sets for symptoms associated with cancer treatment, as based on National Hospice and Palliative Care Organization (NHPCO) and American Society of Clinical Oncology (ASCO) guidelines.

Strategy 5: Develop and implement a plan for palliative care programs that includes appropriate use of rehabilitation services designed to improve the cancer survivorsquality of life.

Strategy 6: Educate healthcare providers and cancer patients, including children, about symptom management, palliative care, and hospice programs.

Strategy 7: Identify availability of hospice care in rural areas, assess gaps in availability and barriers to accessibility and utilization; design and implement strategies to improve availability, accessibility, and utilization.

Hospice: A model of care that can be delivered in a variety of settings, and which employs pain and symptom management within a defined end-of-life period of less than six months.

Follow-Up Care: It is natural for anyone who has completed cancer treatment to be concerned about what the future holds. Many people are concerned about the way they look and feel, and about whether the cancer will recur. They wonder what they can do to keep the cancer from coming back. They also want to know how often to see the doctor for appointments, and what tests they should have. Understanding what to expect after cancer treatment can help patients and their loved ones plan for follow-up care, make lifestyle changes, and reach decisions about quality of life and finances.

Follow-up care involves regular medical checkups that include a review of a patient-s medical history and a physical exam. It is important because it helps to identify changes in health. The main purpose is to check for the return of cancer in the primary site (recurrence), or the spread of cancer to another part of the body (metastasis). Many times, recurrences are suspected or found by patients themselves between scheduled checkups. It is important for patients to be aware of changes in their health, and report any problems to their doctor. The doctor can determine whether the problems are related to the cancer, the treatment the patient received, or an unrelated health problem. For more information, visit: <a href="http://cis.nci.nih.gov/fact.">http://cis.nci.nih.gov/fact.</a>

Goal II: Empower cancer survivors and their families to maximize control over their lives and the disease through the appropriate use of resources and deliberate end-of-life decisions.

Objective II.1: Identify and add to the cancer quality of life resources available to survivors, families and employers. Help ensure their ability to identify their roles, responsibilities and rights.

Baseline: A comprehensive cancer quality of life resource list is unavailable.

Outcomes: By 2008, a quality of life resource list will be available to cancer survivors, their families and employers. By 2011, the level of resources will increase by a percentage to be determined once a baseline has been established.

Data sources: Process evaluation results; quantitative evaluation results comparing baseline resources available with those available in 2011

Strategy 1: Identify resources that describe roles, responsibilities and rights attendant to cancer care and quality of life. Create a database designed to educate cancer survivors, family members, and employers. Add the quality of life resource list to the "Cancer Resource Roster" on the Cancer Control webpage.

Strategy 2: Add the resources available to facilitate access to psychological, physical, social, emotional, vocational, economic, and spiritual support services to the cancer quality of life resource list.

Strategy 3: Analyze gaps and barriers to quality of life cancer services, and implement strategies to overcome them.

Strategy 4: Develop and distribute new and existing resources including patient educational materials, roles and responsibilities, treatment options, common symptoms management, patients=rights, legal, and ethical end-of-life options.

Strategy 5: Increase awareness and encourage expansion of support groups as a tool to help survivors and their families meet their psychological, physical, social, emotional, vocational, economic, and spiritual needs.

Strategy 6: Promote outreach to improve access to these support groups for survivors, families, and employers in smaller communities.

Strategy 7: Make information on return-to-work and other aftercare issues available to survivors.

While it may be reasonable to hope for a long life, it is also possible to hope for different things -- being comfortable...being supported by loving care...having the time to review the past and to take pleasure from it...taking the opportunity to resolve problems and to continue to love and be loved. Adapted from the National Coalition for Cancer Survivorship.

The Americans with Disabilities Act (ADA) calls for employers to provide Areasonable

accommodation@ for workers with disabilities, which may include anything from special equipment or lighting to flexible schedules. The Family and Medical Leave Act (FMLA) requires many employers to allow unpaid, job-protected leave. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) has helped ensure that pre-existing conditions may not be excluded in certain new health policies if gaps in coverage are relatively short.

Objective II.2: Increase the number of cancer patients who have access to advanced healthcare directives through their healthcare providers.

Baseline: To be determined.

Outcomes: By 2008, determine the number of healthcare providers who make advanced healthcare directive planning available to their cancer patients By 2011, improve the number of healthcare providers making advanced healthcare directive planning available by a percent to be determined.

Data sources: Healthcare provider survey.

Strategy 1: Determine the baseline number of healthcare providers assisting with advance healthcare directive planning.

Strategy 2: Review and assess the status of Montana State Law pertinent to advance healthcare directive planning.

Strategy 3: Work with the Palliative Care Summit Workgroup to develop strategies that will encourage healthcare providers to make advanced healthcare directives planning available to their cancer patients.

Strategy 4: Educate healthcare providers about the availability and use of advanced healthcare directives, including living wills, Durable Medical Power of Attorney forms, "Five Wishes", and the Montana Choices Bank Repository Act, a voluntary registry for consumers who wish to ensure that their healthcare providers have access to their advanced healthcare directives.

Strategy 5: Identify and review problems with "Comfort One" and consider implementing a Physician Orders for Life Sustaining Treatment (POLST) form similar to those used in Washington, Oregon, and West Virginia.

Objective II.3: Develop and communicate a Patient-s Bill of Rights for cancer care.

Baseline: A standardized Patient-s Bill of Rights for cancer care has not been developed.

Outcomes: By 2008, determine baseline data on the status of a Patient-s Bill of Rights in Montana. By 2011, begin promoting a standardized Montana Patient's Bill of Rights for cancer care.

Data sources: Process evaluation results

Strategy 1: Gather and review Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards for Patients Bill of Rights; review status of Montana state laws as well as clinical standards recommended by the National Consensus Project for Quality Palliative Care.

Strategy 2: Draft a prototype Patients Bill of Rights for cancer care in Montana. Strategy 3: Determine whether the implementation of a standardized Patients Bill of Rights for cancer care should be initiated at the legislative or voluntary level, and promote implementation in the appropriate venue.

5 Wishes: The Five Wishes articulate your desires to your family and doctors.

- 1. Who you want to make healthcare decisions for you if you can't make them for yourself.
- 2. What kind of medical treatment you want...or don-t want.
- 3. How comfortable you want to be.
- 4. How you want people to treat you.
- 5. What you want your loved ones to know.

Profile: Cindy Peterson had a cough she couldn shake, and she was short of breath. She tried antibiotics, but they didn# help. When she was still coughing the next week, she asked for another prescription. Instead the doctor listened very carefully to her chest. All don=t like the way that sounds,@he said. All want you to get an x-ray right now.@ Cindy had the x-ray. And then another. Shortly after that, they drained two liters of fluid from her lungs. Cindy is a nurse, and the color of the fluid terrified her. The only time she=d seen fluid that color, it had been in a patient with metastatic cancer. The doctor really didn=t need to give her the news. She already knew. When he came into her office the next day, she started to cry as soon as he shut the door. Her doctor referred her to a gynecological oncologist in Spokane. They scheduled surgery immediately. Cindy was in the hospital for a week, then came back to Montana for chemotherapy. In the meantime, she started educating herself. She didn-t have any illusions: the literature was grim. She had stage IV ovarian cancer, and the five-year survival rate was five percent. Cindy joined a clinical trial right away, and received excellent treatment from her doctor in Great Falls. It-s now been two and a half years since she first learned that she had cancer. Cindy has always had a positive outlook on life. Even though the cancer diagnosis was hard to accept, she knew she had to face the challenges ahead. Her choices were to accept the fate the statistics dictated, or take control of her own fate and defy the statistics. She chose to take control. She started small, by setting attainable life goals. She wanted to see her kids graduate from college. Now she wants to see her kids get married and to spoil grandkids. After that, she says she | set new goals.

ABe informed, not afraid. A positive attitude helps. Educating yourself helps, too. The internet is a wonderful tool -- use it to inform yourself, but don=t just accept everything you read. No matter how bad the odds are, there are exceptions. People do survive. And if it isn=t about survival, it=s about quality of life. Don=t look for death, look for life. I

really started looking at the three Fs differently, Faith, Friends, Family. I need my family to get through this, and my family needs me. I intend to be there for them. (Cindy Peterson).

What is a Durable Medical Power of Attorney? A legal document that allows an individual the opportunity to legally authorize a trusted family member or friend to make healthcare decisions at such time as s/he can no longer do so. The Durable Medical Power of Attorney goes into effect immediately after execution and delivery to the agent, and remains in effect until terminated or revoked.

## The Patient-s Bill of Rights

- 1. Information disclosure: You have the right to accurate and easy-to-understand information about your health plan, healthcare professionals and facilities.
- 2. Choice of providers and plans: You have the right to a choice of healthcare providers who can provide access to appropriate high-quality health care.
- 3. Access to emergency services: If you have severe pain, an injury or sudden illness that convinces you that your health is in serious jeopardy, you have the right to receive screening and stabilization emergency services whenever and wherever needed, without prior authorization or financial penalty.
- 4. Participation in treatment decisions: You have the right to know your treatment options and to participate in decisions about your care. Family members or your designees may represent you if necessary.
- 5. Respect and nondiscrimination: You have the right to considerate, respectful and nondiscriminatory care.
- 6. Confidentiality of health information: You have the right to talk in confidence with healthcare providers and to have your healthcare information protected. You also have the right to review, copy, and request corrections to your own medical record.
- 7. Complaints and appeals: You have the right to a fair, fast, and objective review of any complaint you have against your health plan, doctors, hospitals, or other healthcare personnel. This includes complaints about waiting times, operating hours, the conduct of healthcare personnel, and the adequacy of healthcare facilities. Adapted from the Patients Bill of Rights used by the U.S. Advisory Commission on Consumer Protection and Quality in the Health Care Industry. (<a href="https://www.cancer.org">www.cancer.org</a>)

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.

Goal III: Ensure childhood cancer survivors are provided age-appropriate services.

Objective III.1: Establish and implement methods to assist school administrators, teachers and students with the unique challenges presented by children with cancer and their siblings.

Baseline: There is no consistent approach by schools for addressing the needs of children affected by cancer.

Outcomes: By 2010, define and implement methods for addressing the educational needs of children affected by cancer.

Data sources: Process evaluation results.

Strategy 1: Identify the challenges and emotional needs of children with cancer, their siblings, and families correlated with school reintegration activities.

Strategy 2: Research best practice models and develop age-appropriate methods to address identified educational needs.

Strategy 3: Develop creative alternative education plans for children cancer survivors.

Strategy 4: Develop and provide in-service training and continuing education opportunities for educators who work with childhood cancer survivors and their siblings. Objective III.2: Identify the non-educational needs unique to children with cancer and their siblings.

Baseline: A children-s special needs resource list has not been identified.

Outcomes: By 2010, develop, distribute, and maintain a special needs resource list.

Data sources: Process evaluation results.

Strategy 1: Establish a committee to identify the non-educational needs unique to children with cancer and their siblings.

Strategy 2: Develop and routinely update a comprehensive list of the resources available to pediatric cancer patients in Montana, such as specialty services, wig programs, camps, scholarships, wish-granting organizations and home health agencies. Add the resource list to the "Cancer Resource Roster" on the Cancer Control webpage.

Strategy 3: Determine existing resource and service gaps and develop strategies to address the disparities, overcome the barriers, and fill the gaps.

Strategy 4: Develop an information distribution plan to reach all newly diagnosed pediatric cancer patients and their families.

How to Help Children with Cancer in Your Community

- 1. Support local fundraisers.
- 2. Volunteer your time to local nonprofits that work with children who have cancer.
- 3. Advocate for the state and federal policies that will assist children with cancer and their families with their travel and treatment needs.

Goal IV: Ensure that there are opportunities for safe and effective use of complementary medicine in cancer care in Montana.

Objective IV.1: Increase patient, healthcare provider, and institutional awareness of the available complementary therapies from which cancer patients have been shown to

benefit.

Baseline: No baseline data describing the level of awareness of complementary cancer therapies is available.

Outcomes: By 2008, determine how many accredited educational presentations on complementary cancer therapies are available.

By 2011, increase the number of accredited educational presentations on complementary cancer therapies by a percent to be determined.

Data sources: To be established.

Strategy 1: Conduct a study to determine how many accredited educational courses that address complementary cancer therapies are available to Montana survivors, healthcare providers, and institutions.

Strategy 2: Educate allopathic/osteopathic healthcare providers on the potential contribution of complementary therapies and American Indian therapies in cancer care.

Strategy 3: Educate patients on the potential harm associated with self-prescribed care.

Strategy 4: Educate allopathic/osteopathic healthcare providers and patients about the difference between licensed and unlicensed complementary care providers.

Strategy 5: Establish a method whereby allopathic/osteopathic providers and patients can easily identify and access licensed naturopathic providers as well as other licensed or certified complementary care providers.

Strategy 6: Develop tools to improve communication between complementary healthcare providers and allopathic healthcare providers, and educate cancer patients to communicate information about medications, care plans and supplements to all their healthcare providers.

Naturopathic physicians are licensed in Montana as primary healthcare providers. They have broad training and can contribute and participate in many aspects of cancer care, such as data collection, early detection, integrative treatment, quality of life, research, and advocacy. By utilizing the naturopathic physician's expertise in nutrition, lifestyle modification, environmental health issues, and health maintenance, cancer prevention can be maximized.

The American Cancer Society recognizes the need to balance access to complementary therapies, while protecting patients from methods that might be harmful. The ACS supports patient access, but strongly encourages oversight and accountability.

Quality of Life & Survivorship: What You Can Do

- 1. Talk to your healthcare provider about your goals and values for end-of-life decisions, your treatment, and concerns about symptoms and pain management.
- 2. Complete and communicate an advanced healthcare directive.
- 3. Educate yourself about your disease and know what to expect.

- 4. Understand the Patient-s Bill of Rights.
- 5. Support expansion of hospice care availability in frontier and American Indian communities and support programs that enhance quality of life for cancer patients.

Research: The process of scientific discovery is, in effect, a continual flight from wonder. (Albert Einstein)

Clinical trials: Research studies involving people that test new, promising prevention and treatment methods to determine whether they are safe, effective, and better than current standards of care.

The best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged. (National Comprehensive Cancer Network).

Effective methods for Diagnosis, Treatment and Prevention (DTP) of cancer rely on evidence generated from closely-interrelated clinical and basic research. Basic research adds to the understanding of the biology of cancer and is invaluable in designing applications to human disease. Observations of disease development drive basic research studies. Translational research, an intermediate step, links bench science and bedside clinical medicine. Overall, carefully collected and interpreted evidence has the ability to improve outcomes for patients with cancer.

Clinical trials are research studies involving people. They represent the final stages of this long and careful cancer research process. When an approach demonstrates promise, clinical trials or investigations are designed on a scientific data-driven basis to find out if it is safe, effective, and better than the current standard of care. This allows research to advance without compromising current standards of care.

Clinical trials are performed in accredited cancer treatment centers with formal mechanisms that protect the patient, the facility, and the healthcare provider. Patients participating in clinical trials have access to newer, potentially more effective and less costly approaches. The outcomes for the same type and stage of cancer are often better for those participating in clinical trials. They also offer patients and researchers opportunities to contribute to the body of knowledge. Trials have the potential to improve personal care and make lasting contributions to the field of medicine.

Participation in clinical trials is voluntary. Nationally, only two to three percent of cancer patients are treated in clinical trials. Identifying and overcoming barriers to participation can provide better care and data for the emerging advances in cancer management and prevention. Financial and other barriers to participation exist for patients and providers. Health insurance providers may not cover the routine patient care costs for patients in clinical trials.

This Comprehensive Cancer Control Plan proposes a centralized person as a resource for scientifically sound cancer information. The liaison will provide an effective,

coordinated mechanism to increase awareness of cancer-related issues in Montana. The cancer medical liaison will perform multiple tasks.

- 1. Develop and implement tools, including a web-based resource, that provide up-to-date information for patients, healthcare providers, insurance providers, policy makers, and basic researchers. The tools will facilitate participation in basic cancer research, appropriate utilization of translational technology, and increased utilization of clinical trials in Montana.
- 2. Respond to health care professionals by providing access to evidence-based information that improves the effective, efficient use of new technologies as they progress to state-of-the-art and become standards of care.
- 3. Organize educational opportunities through a speakers bureau, seminars, teleconferences, web links, funding opportunities, and translational technology directed toward cancer management.

Basic, translational, and clinical research all offer advances to cancer management. Overcoming barriers to participation in cancer research for both patients and professionals needs to be addressed through educational efforts that are accurate, easy to access, comprehensive, up-to-date, and responsive to need. Through awareness and education, there is an opportunity to reach all populations in Montana that may benefit from cancer research activity in all of its forms.

"The genius, then, is in the bridge or the translation." (Dr. Grant Harrer).

Goal I: Provide professionals and the public with access to cancer research information.

Objective I.1: Create a list of web links relating to science and evidenced-based cancer information.

Baseline: There is no identified comprehensive list of web resources available.

Outcomes: By 2008, a list will be available on-line and routinely maintained.

Data sources: Process evaluation results

Strategy 1: Identify and review possible websites and generate a list of links to science and evidence-based cancer information.

Strategy 2: Maintain the resource list on the Cancer Control webpage, and market this resource to the public and providers.

Objective I.2: Create a position for a liaison to serve as a cancer information resource for healthcare providers and the public.

Baseline: There is no central liaison resource available.

Outcomes: Establish a liaison and make her/him available statewide through a toll-free help line.

Data sources: Process evaluation results.

Strategy 1: Create a job description and identify a physical location and funding for the central liaison. Position duties will include such tasks as: coordination of professional education programs; information management; resource dissemination; and organization of a speakers= bureau, teleconferences, and other activities. Strategy 2: Establish a toll-free help line for access to the liaison and market this resource to providers and the public.

Objective I.3: Establish an educational program on state-of-the-art, cancer-related practices.

Baseline: No comprehensive educational program is available.

Outcomes: By 2011, create and institute a professional educational program on state-of-the-art, cancer-related practices.

Data sources: Process evaluation results.

Strategy 1: Coordinate this program through the central liaison described in Objective 1.2.

Strategy 2: Market this resource to providers and the public. Include information on the program in professional cancer education statewide.

Goal II: Assure high-quality cancer research in Montana.

Objective II.1: Increase the percentage of Montana cancer patients who participate in clinical trials.

Baseline: 2.2 percent of all eligible patients were in clinical National Cancer Institute (NCI) trials in Montana. A percent of patients in other clinical trials will be determined from private companies and other in-house clinical trials.

Outcomes: By 2008, determine the percentage of Montana cancer patients who are participating in clinical trials. By 2011, increase the baseline level of participation by a percentage to be determined.

Data sources: Montana Cancer Consortium (MCCC) 2003 for NCI trials; pharmaceutical, private and in-house clinical trials -- method to be established

Strategy 1: Implement a tool to determine the percentage of Montana cancer patients who are participating in clinical trials.

Strategy 2: Educate healthcare providers and the public on clinical trials available to Montanans of all ages. Provide on-going public education on the benefits and limitations of clinical trials.

Strategy 3: Encourage care coordinators to inform cancer patients of clinical trials germane to their conditions; increase the number of healthcare providers recommending clinical trials to their patients.

Strategy 4: Support policies encouraging insurers to make appropriate reimbursements for routine patient care costs for those in Phase II and III clinical trials.

Strategy 5: Design and implement strategies to increase participation in clinical trials; increase the number and type of clinical trials available in Montana.

Objective II.2: Increase the number of researchers, research dollars, and studies devoted to community-based, clinical, basic science, translational, epidemiologic, genetic, and other cancer-related research.

Baseline: To be determined.

Outcomes: By 2008, determine the baseline for research dollars, studies and researchers in Montana. By 2011, increase funds, active researchers and the number of studies on cancer-related topics by numbers or percentages to be determined.

Data sources: To be established.

Strategy 1: Determine the level of research dollars, number of studies and the number of active researchers working on cancer-related topics in Montana.

Strategy 2: Conduct an assessment to define the supportive infrastructure for research.

Strategy 3: Design strategies to enhance the level of research funding; increase the number of researchers, and improve the infrastructure for cancer research in Montana. Strategy 4: Encourage and facilitate Montana researchers in their applications for cancer-related funding.

Strategy 5: Support increasing culturally competent research in communities and populations with a disparate burden of cancer.

The mission of translational research is to translate basic science into clinical applications, and to use clinical observations to generate scientific research. Translational research focuses on the integration of activities from bench to bedside.

Profile: Patricia Lieberg=s life changed completely in less than a month. Looking back, she realized there=d been signs that something wasn=t quite right. She felt as if she=d pulled some muscles, but couldn=t explain why. She=d developed some facial hair, experienced flushing and shortness of breath. She finally went to see her doctor. He ordered an ultrasound, which revealed what appeared to be a large tumor on her kidney. He referred her to a specialist in Great Falls, who immediately ordered an MRI. The results revealed that the tumor wasn=t on her kidney after all: the adrenal tumor had grown up into the vena cava, the large vein that returns blood to the heart. Patricia

had adrenocortical carcinoma, which affects about one in two million people. After looking at the MRI results, the doctor said, Al don=t even want to touch you here. You need to be in Bethesda, Maryland. They=re the specialists.@ Once there, they removed the adrenal tumor; by then, the tumor had invaded her heart and lungs. The operation went well, and Patricia flew home two weeks later. They-d told her to come back in six months for a follow-up CAT scan. The more she thought about it, the more uncomfortable she became with the idea of waiting. She asked her physician to order a CAT scan locally. It-s a good thing she did: it revealed that the cancer nodules were growing. Neither radiation nor surgery would help. Her best hope was a clinical trial. Patricia agreed to participate in the trial that included new chemotherapy drugs. She has now been through seven treatments in Bethesda, with three or four weeks between treatments. Because she-s participating in a clinical trial, they help with airfare and some of her other expenses. Last time they checked, her doctors were delighted to find that some of the smaller nodules had disappeared, and others had shrunk. It-s great cause for celebration: this cancer is so invasive that the treatment is considered a success if the cancer doesn-t continue to grow.

AThe clinical trial was a great choice for me. Otherwise I=d be dead or close to it by now, the cancer was that bad and had gone that far. My family has been so supportive, but this has changed all of us a lot. You definitely realize what=s important. If I could help others, I=d want to them to know how important it is to keep a positive attitude, and to refuse to give up. There will be down days and days you don=t feel good, but you have to remember there will be good ones, too. Just don=t give up.@ (Patricia Lieberg).

New technology, if used wisely, can yield great benefits. If used indiscriminately, it can add unnecessary costs. Researchers must determine best-use scenarios before promoting wide use. Clinical trials help determine the most efficient, safe, appropriate, and effective use of new technologies.

Research: What You Can Do.

- 1. Become knowledgeable about cancer research in the state.
- 2. Support public policy and legislation promoting increased cancer research and funded cancer research in Montana.
- 3. Become an ambassador for participation in cancer clinical trials and support the application of the information gained from these trials.
- 4. Ask your doctor about clinical trials that you or a family member may agree to participate in.
- 5. Support local fund raisers that provide funding for cancer research in Montana.

The Montana Cancer Consortium is a nonprofit organization whose mission it is to bring state-of-the-art cancer treatment to Montana and Northern Wyoming through clinical trials sponsored by the National Cancer Institute. (www.mtcancer.org).

Data, Registry & Surveillance

"A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment." (Dr. Donna Shalala).

Incidence: The number of new cases of a disease diagnosed each year.

Morbidity: Disease or the incidence of disease within a population. Morbidity also refers to adverse effects caused by a treatment.

Cancer is actually a catch-phrase for many diseases with a wide variety of causes. It can result from genetic predisposition, lifestyle choices, environmental factors, or a combination thereof. Many causes are as yet unknown. Cancer in its many forms represents a major public health issue, as well as a significant challenge to measure and record. Public health agencies rely on several types of information to understand cancer: reports, vital statistics, surveys, assessments of potential exposures, and administrative sources.

Cancer surveillance activities in Montana can be grouped into two main categories: morbidity and mortality information, and risk behavior information. The Montana Vital Statistics Bureau and the Montana Central Tumor Registry (MCTR) conduct surveillance of cancer and mortality. Cancer mortality data is gathered from death certificates.

Cancer is a reportable disease in Montana. The MCTR maintains the data management system on the incidence of various cancers, stage at diagnoses, treatments, and outcomes of cancer and other reportable tumors. This system, which has been in existence since 1979, establishes cancer incidence and relative survival rates. Incident cases -- or the count of each tumor occurrence -- include information such as diagnosis, stage, and treatment. These are submitted to the MCTR by 60 hospitals, two radiation centers, one Veteran's Administration hospital, three pathology laboratories, and many out-of-state cancer registries. Currently, there is no mechanism to report physician-based cancer cases to the MCTR. These cases are estimated to be an additional two to three percent of all cancer tumor incidence.

Surveys on health status, risk behaviors, and life experiences of populations are used to capture prevalence data, which can tell us how widespread a given condition is at a specific point in time.

Modifiable health-risk behaviors are monitored by the Montana Behavioral Risk Factor Surveillance System (BRFSS). This survey of adult Montanans collects information about a number of health behaviors and preventive practices on a continuous basis. These include tobacco use, nutrition, exercise, healthcare, access, and cancerscreening behaviors.

The Environmental Public Health Tracking Project (EPHT) coordinates the collection, integration, analyses, and interpretation of data about exposure to environmental hazards, and its effect on human health. The Department of Public Health and Human

Services (DPHHS) and the Department of Environmental Quality (DEQ) were awarded federal funding in October 2002 to participate in building a national EPHT network, the ultimate goal of which is to integrate data systems nationwide, so that all sectors of the public can take action to prevent and control environmentally related health effects. Existing surveillance systems yield the baseline rates of disease, mortality, or morbidity necessary to detect disease clusters.

Sources of administrative data, including providers, insurers, hospitals, and local health departments also produce health data that could help highlight cancer risks and trends and enhance cancer control efforts, but these data are not readily accessible. Integrating and sharing this data would improve efforts to plan, evaluate, and craft cancer control policy.

Data can help identify areas where greater efforts are needed, potential causes and progress toward reducing cancer mortality. Access to complete, timely, and accurate cancer data is critical to our ability to evaluate progress toward comprehensive cancer prevention and control.

Goal I: Data collected by the Montana Central Tumor Registry will meet the North American Association of Central Cancer Registries (NAACCR) Gold Standard for complete, high quality and timely data.

Objective I.1: Improve reporting of reportable cancer cases to the MCTR within 24 months of the close of the diagnosis year.

Baseline: Currently, there is 92.1 percent case ascertainment within 24 months of year end (MCTR 2002)

Outcomes: By 2010, increase ascertainment within 24 months of year end to 95

percent

Data sources: MCTR

Strategy 1: Analyze barriers to reporting and utilize physician input and other states= procedures to design a process that will educate healthcare providers and facilitate the reporting of tumors.

Strategy 2: Review other data sources including hospital cancer registrars, physicians= offices, the Office of Vital Statistics, Indian Health Services (IHS) and the Montana Breast & Cervical Health Program (MBCHP).

Strategy 3: Evaluate case ascertainment on American Indian Reservations and develop a mechanism for collecting missing data.

Strategy 4: Review Apathology only@ cases and contact primary physicians to obtain reportable data on missing cases.

Strategy 5: Evaluate existing, and develop new, data exchange agreements that encourage other states to collect and provide data to MCTR on Montana cancer patients treated in those states.

Objective I.2: Decrease the percentage of Arace unknown@ and Adeath certificate only@ cases reported.

Baseline: Among reported cancer cases, 4.2 percent are categorized as "race unknown" and 5 percent as "death certificate only" (MCTR 2002)

Outcomes: By 2010, reduce those categorized as "race unknown" to 3 percent; reduce those listed as "death certificate only" to 3 percent.

Data sources: MCTR

Strategy 1: Analyze source of Arace unknown@ and Adeath certificate only@ designations and design strategies for implementation to improve reporting.

Strategy 2: MCTR will request tumor case information from certifying physicians and hospitals where death occurred.

## What is Reportable?

- 1. All malignant cancers (including in-situ) except basal cell carcinoma or squamous cell carcinoma of the skin.
- 2. All benign tumors of the brain.
- 3. All carcinoid tumors.

What is Adeath certificate only"? A cancer case that has been reported to the MCTR based on a cancer diagnosis on the death certificate.

Why is this important? A high percentage of "death certificate only" cases in the MCTR could indicate under-reporting of cancer cases by hospitals and physicians.

Goal II: Analyze and disseminate cancer-related data.

Objective II.1: Increase the dissemination and use of Montana Central Tumor Registry data.

The Montana Central Tumor Registry (MCTR) is the primary cancer-surveillance tool in Montana. The MCTR maintains a data management system that tracks the occurrence and characteristics of cancer and other reportable tumors. It collects information on such things as demographics, staging, treatment, follow-up, and outcomes. The data are gathered for all Montanans regardless of whether or not they are treated here.

Baseline: The MCTR currently publishes a biennial report.

Outcomes: Publish the MCTR report annually and post on the Cancer Control Section webpage.

Data sources: Process outcome results.

Strategy 1: Publish and disseminate an annual MCTR report, to include education on MCTR, risk factor data, incidence by tumor type, mortality, and benchmark comparisons. Add to the Cancer Control webpage.

Strategy 2: Regularly assess and disseminate information on the cancer burden in Montana utilizing existing data sources. Identify the need for additional data sources and work toward establishing data links.

Strategy 3: Promote use of the MCTR data in cancer research publications. Develop creative avenues to present cancer-related data, such as utilizing Geographic Information Systems (GIS) data maps.

Cancer cluster: A statistically significant, greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a period of time.

Objective II.2: Increase the amount of cancer cluster information available on the Cancer Control webpage.

Baseline: The cluster investigation protocol is not widely implemented within DPHHS; cancer cluster information is not available on-line.

Outcomes: By 2008, publish cancer cluster educational information on the Cancer Control webpage.

Data sources: Process evaluation results.

Strategy 1: Implement and institutionalize the use of the cancer cluster investigation protocol within DPHHS.

Strategy 2:

- a. Produce a Cancer Control webpage that includes cancer cluster investigation reports and educational information.
- b. Link the Cancer Control webpage to the DPHHS health data website.
- c. Incorporate data from the Montana Central Tumor Registry, Montana Breast and Cervical Health Program and Vital Statistics.

Cancer, in general, is common. According to the American Cancer Society, about 1,399,790 Americans will be diagnosed with cancer in 2006.

ASomewhere, something incredible is waiting to be known. @ Carl Sagan

Objective II.3: Improve the availability, accessibility, and utilization of cancer-related data.

Baseline: There is no cancer-related data resource list; there is no broad-based analysis of cancer using multiple data sources.

Outcomes: By 2008, create a cancer-related data resource list; create a broad-based

cancer analyses; post on the Cancer Control webpage.

Data sources: Process evaluation.

Strategy 1: Compile a list of cancer-related publications and data resources, and add to the "Cancer Resource Roster" on the Cancer Control webpage.

Strategy 2: Post a link on the Cancer Control webpage to the Center for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) and other cancer-related data sources.

Strategy 3: Collect and analyze data on cancer from multiple sources including the MCTR, Vital Statistics, BRFSS, claims, insurance, and admissions data. Identify barriers, gaps, and disparities in the cancer control continuum. Implement interventions to rectify the deficiencies.

Strategy 4: Periodically publish and promote a comprehensive Montana cancer control report. Include updates on the progress of Comprehensive Cancer Control Plan projects.

Strategy 5: Support standardization and integration of databases among Indian Health Service, Montana Breast and Cervical Health Program, the MCTR, the EPHT and the Rocky Mountain Biomonitoring Consortium (RMBC).

Strategy 6: Utilize and support analyses of BRFSS and American Indian survey data to learn more about risk factors. Add appropriate questions to on-going surveys as needed for comprehensive cancer control.

Strategy 7: Develop a taskforce to:

- a. support the Comprehensive Cancer Control Programs internal and external data needs.
- 2. work with the cancer epidemiologist.
- 3. identify gaps, needs, disparities, and barriers in cancer data and determine interventions to rectify the deficiencies.

Strategy 8: Establish new data sources for use in assessing, strategizing, and prioritizing future comprehensive cancer control activities.

Some racial and ethnic groups have higher incidences of, and deaths due to, cancer. Such disparities may be due to multiple factors, such as the late stage of disease at diagnosis, barriers to healthcare access, biologic and genetic differences, health behaviors, cultural differences, exposures to carcinogens in the environment and the workplace, and other risk factors.

Objective II.4: Collaborate with Montana's Environmental Public Health Tracking project to establish integrated databases that allow epidemiological investigations of health hazards from environmental exposures and other sources.

Baseline: Databases are not currently integrated.

Outcomes: By 2011, integrate data sets from the MCTR and the MBCHP; integrate data sets from the remaining agencies listed in Strategy 1.

Data Sources: Process evaluation results.

Strategy 1: Collaborate with the DPHHS Environmental Public Health Tracking project to integrate cancer-related databases, including MCTR, and MBCHP data as well as other existing or emerging sources of environmental or health-related data (e.g., Department of Environmental Quality, data from other DPHHS divisions, the Environmental Protection Agency, Agency for Toxic Substance and Disease Registry (ATSDR), the Occupational Safety and Health Administration (OSHA), and the United States Department of Agriculture (USDA).

Strategy 2: Support creation of the information technology needed to enhance cancer data collection, as through the Informatics Section of the Public Health Improvement and Preparedness Bureau.

Strategy 3: Increase access to cancer-related data for epidemiological analyses by working with the Health Planning Section of DPHHS to establish a Montana Interactive Health Database website for data analyses.

Strategy 4: Disseminate results derived from a newly established Montana Interactive Health Database to allow comparative analyses over time and establish trends in cancer related health conditions in Montana for use in assessing progress and making comparative analyses.

Strategy 5: Promote the use of datasets by epidemiologists and public health agencies to improve knowledge, enhance investigations, and create risk-reduction strategies and guidelines for cancer care in Montana.

Timeline for Available Data: Hospitals report abstracted information on cancer patients that are diagnosed and treated, usually after the patient has completed treatment. Treatment can take six months or more. After the cancer case is submitted to the MCTR, the case is entered into the MCTR database and checked for quality. Over 100 data variables are checked for consistency and validity. Sometimes, hospitals need to be contacted for more information. Yearly data are not available for about 12 to 18 months after the year-end, so hospitals have time to report all their cases and the MCTR staff has time to enter and review every case. On average, a hospital needs one hour to abstract one cancer case. After the MCTR receives the abstracts, they need one-half to one hour for each cancer case.

CDC's one-stop shop for environmental public health data: http://www.cdc.gov/nceh/tracking/resources data.htm

Profile: Lou Olcott is the Biomonitoring Program Manager and Laboratory Training Coordinator for the Laboratory Services Bureau of the Department of Public Health and Human Services. She and Dr. Kammy Johnson work with the Rocky Mountain Biomonitoring Consortium (RMBC), formed through a grant award from the Centers for Disease Control and Prevention in 2002. The proposal was to integrate the biomonitoring program among six states: Montana, Wyoming, Utah, Colorado, Arizona and New Mexico. Each state has a member with an epidemiological background and

laboratory background. All of the states in the consortium have geophysical commonalities and similar contamination issues. The RMBC includes large border states with sparse populations, few population centers and a history of mining and smelting.

Biomonitoring assesses human exposure to toxic substances by the laboratory measurement of these substances or their metabolites. The biomonitoring project will include establishment of baseline data for environmental toxins. The Consortiumn's primary objective is to increase existing laboratory capabilities and capacity within the region, and conduct biomonitoring as funds permit. The goal of the RMBC is to implement and expand the regional laboratory based biomonitoring program to:

- 1. develop laboratory capacity to monitor human exposure to environmental chemicals.
- 2. determine the number of people in the RMBC region exposed to environmental chemicals, as well as the degree of their exposure.
- 3. increase the capacity of the RMBC states and local health departments to deliver the environmental health services that help prevent disease resulting from exposure to toxic substances.
- 4. work closely with local partners and other governmental entities to protect the health and well being of our citizens.

#### Resource List:

- 1. Cancer Control Planet: cancercontrolplanet.cancer.gov
- 2. Cancer in Montana Annual Report: www.cancer.mt.gov
- 3. Behavior Risk Factor Surveillance System: www.dphhs.mt.gov/hpsd/BRFSS
- 4. Environmental Public Health Tracking: www.dphhs.mt.gov/epht
- 5. North American Association of Central Cancer Registries: www.naaccr.org
- 6. American Cancer Society: www.cancer.org
- 7. CDC's Cancer Prevention and Control Program: www.cdc.org/cancer
- 8. The National Institutes of Health's National Cancer Institute (NCI): www.cancer.gov/cancer\_information
- 9. NCI Cancer Progress Reports: progressreport.cancer.gov
- 10. National Toxicology Program: http://ntp-server.niehs.nih.gov

Data, Registry & Surveillance: What You Can Do.

- 1. Support data collection strategies. Participate in the BRFSS survey if called upon to do so.
- 2. Ask your legislators to support:
- a. the MCTR and EPHT
- b. acquisition of hospital discharge data for information about cancer in Montana
- 3. Utilize the information in Montana=s cancer reports to understand and increase your knowledge about cancer and to reduce your risks.

## Advocacy

AAdvocacy is the pursuit of influencing outcomes -- including public policy and resource allocation decisions within political, economic, and social systems and institutions -- that directly affect lives. (David Cohen, Co-Director, Advocacy Institute).

Advocacy can mean many things for many different people and situations. For the purposes of this plan, advocacy refers to developing the public health infrastructure needed to implement the Montana Comprehensive Cancer Control (CCC) Plan. It also refers to advancing the legislative policy that can improve the ability to prevent and treat cancer, and improve survivors= quality of life from diagnosis through the course of the disease.

Montana=s public health system is made up of a complex network of people, systems, and organizations in public and the private sectors. By improving the infrastructure we are strengthening all parts of the public health system that work to execute the Montana CCC Plan. Public policy can result in better healthcare, support for research, and the creation of an effective infrastructure. Collectively, these can lead to reductions in cancer incidence and mortality.

Besides being a medical, social, psychological, and economic issue, cancer is a political issue. Lawmakers at all levels make decisions that impact our ability to reach our cancer control goals. For example, decision makers determine how much money goes into cancer research, the policies that affect the public health infrastructure, and state funding levels for public health.

Public health policy impacts thousands and is a critical tool for realizing the goals of this plan. Educating the public, the media, and decision makers about the importance of sound policy could ultimately reduce cancer incidence and mortality rates and improve cancer survivors= quality of life.

Profile: John Bohlinger

John Bohlinger is the Lieutenant Governor of Montana and a cancer survivor. He is quick to say how important it is to be open about his experience, and believes that by talking about cancer, we can begin to effect change.

John got a physical exam every year, so he was well aware of the fact that his PSA levels had started creeping up. The prostate-specific antigen (PSA) is a protein produced by the cells of the prostate gland. The PSA test, which measures the levels of the antigen in the blood, went from one the first year, to two the next, then four, then eight. Year-by-year, it was doubling. He was 58 years old when he learned that he had prostate cancer.

He started educating himself. He researched the disease on the internet, discussed it with his doctor, his wife, family, and friends. After a lot of thought, John decided that surgery was his best and safest option, particularly since he had a very strong family history of the disease. John's father was 49 when he died, and John lost his mother a

few years afterward. Both died of cancer. It came down to the fact that he wanted to eliminate the presence of cancer altogether. The surgery went well, and John has been a survivor for more than six years.

Al believe it's important to tell our stories. My wife, Bette, offered a shining example of courage and grace in the face of adversity. It isn't just about surviving – it's how we live that defines us." (Lt. Governor John Bohlinger).

Profile: Bette Bohlinger was always been moderate in her habits. She ate right, exercised every day, watched her weight, and she=d gotten a clean bill of health from a physical in October. Because her mother had been diagnosed with breast cancer when Bette was a little girl, she had always worked hard to avoid the risk factors that can lead to cancer. It seemed to pay off. She was healthy, active, and had lots of energy. She=d needed that energy for the past year while she and husband, John, worked on a vigorous gubernatorial campaign for Brian Schweitzer. When Brian Schweitzer won the race for governor, she and John were jubilant. Life was good. They were ready to celebrate by meeting their family in Big Sky for a four-day Thanksgiving holiday. As soon as they arrived, though, Bette developed a severe headache she couldn=t shake.

As soon as she got home to Billings, she went to see her doctor. The doctor asked if there-d been other symptoms. ANothing except some bruising I can-t explain, Bette paused, and then, remembering something she-d read, AMaybe you should test me for leukemia. She was half joking, and was surprised when her doctor took the suggestion seriously.

Bette was stunned when she learned that she had acute myeloid leukemia. Her platelet level was so low that her headache had actually been caused by bleeding on the surface of her brain. She started treatment the same day, and she was given a 10-20 percent chance of survival for one year.

Al was stunned when I learned that I had leukemia, Bette said. Al-d practically been the poster child for moderation. Suddenly I found myself thinking that it hadn-t mattered after all. But I-ve since changed my mind. I-ve recovered much more quickly than anyone expected, and I know it-s because I-ve lived such a healthy life.

It was touch and go for months. For several days running, she had a temperature of 106 degrees. Her treatment team had no option but to put her on a sheet of ice water to try to bring down the fever. Her kidneys and liver started to fail, and her heart was racing at 140 beats per minute. Bette says she doesn-t remember those days. John does. With tears in his eyes, he remembers the doctor coming by early one morning to say, Al-m not sure that she-s going to live through this day. Call your kids and tell them to come say goodbye to their mother. All six of the Bohlinger-s children came, from all points of the country.

Day by day, Bette survived. She attributed much of it to the wonderful care she received. Chemotherapy lasted from the end of November until the first of May. Her

hair had grown back and food had begun to taste good again when she went in for her three-month check-up. They found no evidence of cancer, and her doctors said her chances of survival had grown to 60-70 percent for one year. She was thankful they continued to grow with every passing day.

Update: Montana suffered a grievous loss when Bette Bohlinger succumbed to cancer in January 2006.

AOne thing that really helped me was the big stack of cards and letters I received every day, many from people I didn± even know. It helped to know that people were praying for me and thinking of me, to know that people cared. If I could pass on two things I=ve learned from all this, I would encourage people to take care of themselves, and to be open about their cancer experiences. Share your story. Speak out. We can use our stories to give others hope. (Bette Bohlinger).

Goal I: Implement Montana-s Comprehensive Cancer Control Plan.

Objective I.1: Increase political support for public health and implementation of the Montana CCC Plan.

Baseline: During the 2005 Montana Legislative Session, two bills and one Senate Joint Resolution were introduced that had a direct connection to cancer, and none mentioned the Montana CCC Plan.

Outcomes: Cancer will be raised as a campaign issue during the next several political cycles, and an increased number of resolutions and/or bills addressing cancer-related issues will be presented during the legislative sessions and in the U.S. Congress. By 2006, establish baseline number of U.S. congressional bills with a direct connection to cancer.

Data sources: Montana legislative website; American Cancer Society (ACS) Legislative Survey; the ACS National Government Relations Department.

Strategy 1: Determine the number of U.S. congressional bills with a direct connection to cancer.

Strategy 2: Determine baseline levels of knowledge and legislative support for the Montana CCC Plan and public health infrastructure by adding CCC related questions to the American Cancer Society Legislative Survey in 2006.

Strategy 3: Develop state and federal political support for the Montana CCC Plan and the public health infrastructure needed for its implementation.

Strategy 4: Establish a legislative taskforce for the Montana Cancer Control Coalition (MTCCC) in 2005. Link cancer-related legislation to the Montana CCC Plan.

Strategy 5: Educate and update state and federal legislators on the Montana CCC Plan and progress toward implementation and outcomes:

a. Generate an annual progress report

- b. Provide progress reports to legislative leadership and committees working on health-related issues.
- c. Provide state, tribal and federal legislators with MTCCC position papers on key issues.

Strategy 6: Involve state, tribal and federal legislators in implementing the Montana CCC Plan.

Strategy 7: Build a base of advocacy for the Montana CCC Plan and affiliated stakeholder groups. Identify policies that can support the plan.

Strategy 8: Educate cancer survivors and their loved ones on the importance of being involved in the political process in a variety of ways including voting, serving on committees and taskforces, serving as lawmakers, lobbying, and educating. Strategy 9: Develop guidelines for MTCCC members to use when working with legislators and decision makers. Communicate priority legislative issues to stakeholders and healthcare providers with position papers.

American Cancer Society contact information, call toll free, 1-800-227-2345.

Advocate, Participate, Update, Motivate, Educate, Legislate:

### Advocacy Websites

- 1. www.acscan.org
- 2. www.canceradvocacynow.org
- 3. www.plwc.org
- 4. www.cancercare.org
- 5. www.cancersurvivaltoolbox.org/
- 6. www.cdc.gov/cancer/survivorship
- 7. www.cansearch.org/policy

Objective I.2: Increase public support for Montana = s CCC Plan.

Montana has the 31st highest overall cancer incidence rate and the 33rd highest overall mortality rate among the 50 states and the District of Columbia.

Baseline: There is limited awareness of the CCC Plan, as reflected by the fact that there were no news items mentioning the Montana Comprehensive Cancer Control Plan in 2004.

Outcomes: Beginning in 2005, public interest in, and awareness of, the Montana CCC Plan and the issues surrounding cancer will increase annually.

Data sources: Results of media coverage tracking; annual number of hits on the Cancer Control webpage; number attending periodic Montana Cancer Control conferences.

Strategy 1: Track coverage of comprehensive cancer control activities in the media, hits

on the webpage, and attendance at Montana Cancer Control conferences.

Strategy 2: Refer to the CCC Plan when implementing each strategy and tactic.

Strategy 3: Develop and execute a communication plan for the implementation process that includes press releases, the webpage, presentations, and other materials.

Strategy 4: Hold statewide public forums during fall 2005 to introduce the draft CCC Plan.

Strategy 5: Sponsor periodic Cancer Control conferences; use as venues to promote the Montana CCC Plan.

Strategy 6: Distribute an annual progress report.

Strategy 7: Engage the media:

- 1. Develop relationships with Montana-s media outlets.
- 2. Provide the plan to the media.
- 3. Periodically provide the media with updates.
- 4. Provide media with story ideas on the face of cancer.

Strategy 8: Provide multiple opportunities for the public to participate in the implementation process.

ASurvivors face numerous issues throughout their diagnosis and treatment, and for the remaining years of their lives. Many of these issues could be addressed through coordinated public health initiatives. (A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies).

Objective I.3: Build the capacity needed in the Department of Public Health and Human Services (DPHHS) staff and Montana Cancer Control Coalition infrastructures to execute the CCC Plan.

Baseline: Existing communication systems and staffing time dedicated to implementing the Montana CCC Plan.

Outcomes: By 2007, fill the positions (private and public) necessary to execute the CCC Plan; implement the plan within the established timelines; establish a functioning listsery; ensure that all legislators and key decision makers know of the CCC Plan as they move into the 2007 and 2009 legislative sessions.

Data sources: DPHHS and stakeholder reports; legislative poll.

Strategy 1: Develop the internal and external communication structure to carry out the implementation process and build the relationships needed to foster an environment conducive to change.

- a.. Develop communication systems within DPHHS, the Chronic Disease Department, the steering committee, and other key stakeholders.
- b. Develop an external communication system to educate and involve medical associations, medical service providers, private sectors, state administration, state legislature, congressional delegates, survivors, tribal governments, media, other chronic disease groups, and local communities.

c. Create a listsery for stakeholders to communicate with one another.

Strategy 2: Develop and/or revisit a clear understanding of stakeholder roles and responsibilities within the context of implementation.

Strategy 3: Develop a plan to expand public health infrastructure and the infrastructure to support the Montana Cancer Control Coalition.

- 1. Assess existing infrastructure; identify and resolve gaps.
- 2. Identify and provide the training and technical assistance necessary to execute the CCC Plan.
- 3. Clearly define a timeline with checkpoints and accountability.

Objective I.4: Secure the resources needed to execute the CCC Plan.

Baseline: The Centers for Disease Control and Prevention (CDC) implementation grant.

Outcomes: By 2007, raise the in-kind and cash resources needed to execute the key strategies of the CCC Plan.

Data sources: Montana CCC program financial reports; periodic stakeholder reports to be established.

Strategy 1: Establish an expertise workgroup to work with public, private and nonprofit stakeholders to identify existing in-kind and cash resources that can be utilized for implementation; periodically poll stakeholders about the resources used for plan implementation.

Strategy 2: Assess existing infrastructure for resource needs.

Strategy 3: Develop and execute a resource acquisition plan that includes making requests to private and nonprofit stakeholders and identifying the funding roles of local, state, and federal governments.

ANever doubt that a small group of thoughtful committed citizens can change the world. Indeed, it=s the only thing that ever has.@ (Margaret Mead).

Profile: Lois Fitzpatrick is a medical librarian and a ten-year survivor of breast cancer. She was the one who found her cancer -- she spotted a dimple in the mirror, checked, and found a lump. Within two days, she=d gotten in to see her doctor. He didn=t waste any time, either. She found herself at a surgeon=s office almost immediately. Because she is a medical librarian, she=d already done a lot of research. While she was in the operating room for a surgical biopsy, she heard the doctors say something about a frozen section and she knew it was cancer. Lois had the biopsy on Monday; on Thursday she had a lumpectomy. The cancer was Stage One, and hadn=t spread to the lymph nodes.

Lois had just turned 43 and had two young daughters at home. She was terrified that she wouldn t see her daughters finish growing up. She got several opinions on next

steps, and thoroughly researched them. Ultimately she decided to fight back aggressively, with everything she could. Lois chose to undergo chemotherapy, radiation, and hormone therapy.

Al wanted to beat the life out of the cancer, so I went through the whole series. I would do it again. In retrospect, I made all the right decisions. First I advocated for myself by doing my research. I decided I had to be a 100 percent full participant. I wanted to be very clear that this was not going to be something I was doing for myself.@

The ten years of survivorship have been busy ones. Lois talks with many women who have breast cancer, and shes worked with the American Cancer Society, Susan B. Komen, and has become certified as a breast self-exam instructor. When shes working with women, she encourages them to ask the hard questions. Lois believes that information is power, and shes working hard to empower other women.

All try to help others. I lobby to get bills through. I get the word out. I want to be a voice for those women who can-t speak for themselves. That-s why I lobby; why I testify. We-ve got to keep finding new and better ways to beat this thing. (Lois Fitzpatrick).

Suggestions for effective communication with a healthcare team:

- 1. Become a partner and actively participate in the cancer care plan.
- 2. Develop and expect an attitude of respect and cooperation.
- 3. Provide accurate information about family history.
- 4. Keep a list of questions for doctors or other team members.
- 5. Take notes when having important conversations with doctors.
- 6. Ask for explanations of anything you don't understand.
- 7. Inform team members of concerns.
- 8. Have reasonable expectations about the time the team members can spend.
- 9. Let team members know the patient's care preferences.
- 10. Develop positive relationships with team members.
- 11. Expect confidentiality.
- 12. Recognize and accept that communication and other problems will occur.
- 13. Address confusion, frustrations, or disagreements directly.

(Adapted from American Cancer Society "Understanding the Healthcare System").

Advocacy: What You Can Do.

- 1. Get involved with the Montana Cancer Control Coalition and comprehensive cancer control activities in your community. Complete and mail the member information form included in this document.
- 2. Talk to your lawmakers about cancer issues, early and often.
- 4. Support funding the Montana Comprehensive Cancer Control Plan implementation projects.
- 5. Attend an annual Montana Cancer Control Conference.

6. Remain informed on cancer control issues.

Implementation, Evaluation and Evolution:

Implementation: The Montana Cancer Control Coalition (MTCCC) is committed to implementing the Montana Comprehensive Cancer Control (CCC) Plan. This will require organizations and members to work together on cancer control activities. The MTCCC has restructured for implementation as indicated in the organizational chart. Description of organizational chart depicting the Montana Cancer Control Coalition. The Steering Committee (represented by a hexagon at top center), interacts with the Communication, Evaluation and Evolution Standing Committees (depicted by a rectangle at top left). It also interacts with the Ad Hoc Committees on Transition, the Cancer Conference, By-laws, and any other ad hoc committees formed as needed (depicted by a rectangle at top right). The Steering Committee also interacts with the Implementation Teams on Prevention, Early Detection, Treatment and Research, and Quality of Life and Survivorship (depicted as an oval at lower left). The Implementation Teams also interact with any Ad Hoc Taskforces (depicted by a hexagon at the bottom center). The Support Expertise Workgroups on Data, Funding and Resources, Education, and Legislation (represented by an oval at lower right) interact with the Steering Committee, provide input to the Implementation Teams and interact with any Ad Hoc Taskforces. End of description.

The responsibilities and roles of the Steering Committee and members have been redefined. The Steering Committee is the governance and decision-making body. Communication, Evaluation, and Evolution will continue as standing committees. Ad hoc committees will form and dissolve as needed.

The Steering Committee will direct implementation activities and establish timelines. It will continue to recruit, maintain memberships, and build partnerships, as well as plan distribution. The Steering Committee will also continue to develop leadership skills among volunteers, guide data and communication priorities, identify resources, and coordinated cancer control activities.

The Communication Committee will develop short- and long-range internal, external and media communication plans.

The Evaluation Committee ensured that CCC Plan objectives are measurable, and include identified data sources, baseline data, and target outcomes whenever possible. This committee will develop the evaluation framework, the evaluation plan, and guide, monitor, and assess the evaluation of the Comprehensive Cancer Control Program, the MTCCC, CCC Plan implementation activities, and outcomes.

The Evolution Committee will prioritize auxiliary and newly strategies using documented criteria, and consider such factors as evaluation results, new opportunities, science, and trends, and use them to make recommendations for change

to the Steering Committee.

MTCCC members have confirmed their commitment to CCC Plan implementation by registering for implementation teams, support expertise workgroups, and standing committees. Implementation teams are organized around the CCC Plan sections of Prevention, Early Detection, Treatment and Research, and Quality of Life and Survivorship. Resources are limited. Prioritization using established criteria will set the order in which objectives and strategies are addressed.

The implementation teams will work together to finalize and implement prioritized strategies. The coalition identified cross-cutting issues and defined workgroups to provide expertise in the areas of data, education, legislation, and funding and resources. The workgroups are utilized for their expertise by the Steering Committee and the teams to research and identify tools, projects, best practices, and resources in their areas of expertise. As implementation progresses, evaluation and evolution will be key to ensuring sustainability.

Montana Cancer Care Coalition Working Together...

Evaluation: Evaluation will consist of four parts:

- 1. Comprehensive Cancer Control Program;
- 2. Montana Cancer Control Coalition:
- 3. CCC Plan implementation process and environment; and
- 4. CCC Plan short, intermediate and long-term outcomes.

The Evaluation Committee will establish an overall evaluation protocol, as well as develop and oversee implantation of an evaluation plan. It will determine the needs, questions, methods, and framework for evaluating the CCC Program, the MTCCC, CCC Plan cancer control activities, and outcomes. The Evaluation Committee will also identify stakeholders who are already implementing CCC Plan activities.

The Evaluation Committee will also assess progress toward stated objectives and outcomes, and toward achieving short- and long-range goals. They will undertake such activities as:

- 1. periodically assessing progress in meeting program goals;
- 2. evaluating the coalition for networking, member satisfaction, technical assistance and educational needs;
- 3. evaluating prioritization and implementation processes and the environment within which implementation occurs; and
- 4. creating and overseeing evaluation plans for cancer control activities, and the process and progress toward outcomes.

The committee will analyze utilization and availability of resources, and internal and external infrastructures. An annual progress report will be presented at a cancer control

conference. Evaluation results will be used to improve the CCC Program, the MTCCC structure and function, the implementation process, change or develop cancer control activities, and improve progress toward desired outcomes.

Program evaluation is a systematic way to learn from past experience, and improve performance and outcomes.

Evolution: The Montana Comprehensive Cancer Control Plan is a living document and an essential starting point for addressing cancer in Montana. The plan will change and evolve with time, information, new opportunities and changing needs. The Evolution Committee will oversee recommendation for change made to the Steering Committee. The critical steps of evolution include:

- 1. continuing to recruit and maintain a broad-based membership;
- 2. creating recommendations based on assessments and using them to implement changes to the program, the coalition and the plan;
- 3. prioritizing ideas, suggestions, new and ongoing strategies based on established criteria, protocols, and evaluation results. Unprioritized issues and ideas from the planning process are available at <a href="https://www.cancer.mt.gov">www.cancer.mt.gov</a> under the "Auxiliary Strategy List". This will be periodically updated and prioritized by the Evolution Committee.
- 4. Adding, changing, or disbanding ad hoc committees and taskforces as projects are completed and priorities emerge;
- 5. sustaining an implementation process that continues to evolve in response to evaluation results, the environment, data, resources, new evidence and science, healthcare trends, opportunities, national programs, and the need for cancer control in Montana;
- 6. continuing a comprehensive, multifaceted approach to decreasing the burden of cancer on Montana.
- 7. ensuring accountability throughout the comprehensive cancer control process through evaluation, response and modification;
- 8. maintaining fidelity to the vision: A comprehensive, statewide, evidence-based approach to reduce the burden of cancer in Montana, motivated by compassion...an investment in the future.

Organizations and individuals interested in joining the MTCCC to implement this plan should complete and return the member information form of this document or online at www.cancer.mt.gov.

#### Resources:

- 1. Agency for Healthcare Research and Quality (AHRQ): <a href="http://www.ahrq.gov/">http://www.ahrq.gov/</a>
- 2. American Cancer Society (including American Cancer Society Facts and Figures): www.cancer.org
- 3. American College of Surgeons, Commission on Cancer: <a href="http://www.facs.org/cancer/coc/coc.html">http://www.facs.org/cancer/coc/coc.html</a>
- 4. American Society of Clinical Oncology (ASCO) People Living With Cancer: www.plwc.org
- 5. Behavioral Risk Factor Surveillance System: <a href="http://www.cdc.gov/brfss/">http://www.cdc.gov/brfss/</a>

- 6. Cancer Care: www.cancercare.org
- 7. Cancer Control Planet : <a href="http://cancercontrolplanet.cancer.gov">http://cancercontrolplanet.cancer.gov</a> (See other statesn CCC

plans)

- 8. Cancer Plan: <a href="http://www.cancerplan.org/">http://www.cancerplan.org/</a>
- 9. C-Change: <a href="http://www.ndoc.org/default.asp">http://www.ndoc.org/default.asp</a>
- 10. Centers for Disease Control and Prevention (CDC): www.cdc.org and

http://www.cdc.gov/od/ads/opspoll1.htm

- 11. CDC Evaluation Working Group: http://www.cdc.gov/eval/framework.htm
- 12. Colorectal Cancer Costs in Montana:

http://gastro.org/pubPolicy/issueBriefs/urges.html

- 13. Council of State Governments: <a href="http://www.healthystates.csg.org/">http://www.healthystates.csg.org/</a>
- 14. Entrez PubMed: www.ncbi.nlm.nih.gov/entrez
- 15. Healthy People 2010: http://www.healthypeople.gov/default.htm
- 16. Lance Armstrong Foundation: http://www.laf.org/
- 17. Montana Central Tumor Registry Annual Report: www.cancer.mt.gov
- 18. Means to a Better End: A Report on Dying in America Today:

www.endoflifecommission.org/end\_pages/national\_report.htm

- 19. Messengers for Health Project: Suzanne Christopher, Ph.D., Principle Investigator. suzanne@montana.edu or 406-994-6321
- 20. National Comprehensive Cancer Control Program:

http://www.cdc.gov/cancer/ncccp/index.htm

- 21. National Cancer Institute (NCI): <a href="www.cancer.gov">www.cancer.gov</a> and National Cancer Institute<a href="mailto:scancer.gov/">Scancer Institute<a href="mailto:scancer.gov/">scancer.gov</a> and National Cancer Institute<a href="mailto:scancer.gov/">scancer.gov/</a>
- 22. NCI Cancer Progress Report: <a href="http://progressreport.cancer.gov/">http://progressreport.cancer.gov/</a>
- 23. National Coalition for Cancer Survivorship www.canceradvocacynow.org
- 24. National Comprehensive Cancer Network <a href="http://www.nccn.org/default.asp">http://www.nccn.org/default.asp</a>
- 25. National Consensus Project on Quality Palliative Care

http://www.nationalconsensusproject.org/index.html

- 26. Partnership For Prevention <a href="http://www.prevent.org/index.cfm">http://www.prevent.org/index.cfm</a>
- 27. Youth Risk Behavior Surveillance System

http://www.cdc.gov/HealthyYouth/yrbs/index.htm; http://www.opi.state.mt.us/

# Glossary:

Alternative medicine: Therapeutic approaches used in place of traditional medicine to treat or ameliorate disease, that do not follow generally accepted medical methods and may not have a scientific explanation for their effectiveness.

Cancer: The umbrella term to describe many different diseases in which cells grow and reproduce out of control.

Cancer Burden: Overall impact of cancer in a community

Carcinogen: Any substance known to cause cancer.

Clinical trials: Research studies that involve patients. Studies are designed to find

ways to prevent, detect, diagnose, or treat cancer and answer scientific questions.

Complementary medicine: Practices used to enhance or complement standard treatments, but which are not recognized as standard or conventional medical approaches.

Culturally competent: Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that enable effective work in cross-cultural situations. Distant stage: Cancer has extension beyond adjacent organs or tissues or metastases to distant site(s) or distant lymph node(s).

Epidemiology: The study of disease incidence and distribution in populations, and the relationship between environment and disease. Cancer epidemiology is the study of cancer incidence and distribution as well as the ways surroundings, occupational hazards, and personal habits may contribute to the development of cancer. Evidence-based: The process of systematically finding, appraising, and using contemporaneous research findings as the basis for clinical decisions Five-year survival: Five-year survival is a term commonly used as the statistical basis for successful treatment. A patient with cancer is generally considered cured after five or more years without recurrence of disease.

Follow-up: Monitoring a person's health over time after treatment. This includes keeping track of the health of people who participate in a clinical study or clinical trail for a period of time, both during the study and after the study ends.

Genetic susceptibility: An inherited increase in the risk of developing a disease. Healthcare professional: Practitioners in disease prevention, detection, treatment, and rehabilitation are known as health care professionals. They include physicians, nurses, dentists, dietitians, health educators, social workers, and therapists, among others. Health disparities: Differences in the incidence, prevalence, mortality and burden of cancer and related adverse health conditions that exist among specific population groups in the United States.

High risk: The chance of developing cancer is greater for an individual or a group of people than for the general population. People may be considered to be at high risk from many factors or combination of factors, including family history, personal habits, or exposure to carcinogens.

Hospice: Special care for people in the final phase of illness, their families and caregivers, usually provided in the patient's home or a homelike facility. Incidence: Incidence is the number of times a disease occurs in a given population. Cancer incidence is the number of new cases of cancer diagnosed each year. The Montana Central Tumor Registry maintains cancer incidence data in Montana. Incidence rate: A measure of the rate at which new events occur in the population. The number of new cases of a specified disease diagnosed or reported during a defined period of time is the numerator, and the number of persons in the stated population in which the cases occurred is the denominator.

Informed decision-making: Choices and preferences stated after the individual understands the nature and risks of their cancer diagnosis and treatment options. Integrative medicine: Combining the best ideas and practices of conventional and alternative medicine into cost-effective treatments in the best interests of patients, to stimulate the potential for natural healing. It neither rejects conventional medicine nor embraces alternative practices uncritically.

Localized stage: Cancer that is limited to the site of origin. There is no evidence of metastasis elsewhere in the body.

Malignancy (or malignant): Cancerous; can invade nearby tissue and spread to other parts of the body.

Metastatic cancer stage: Cancer that has spread from the place in which it started to other parts of the body.

Moderate physical activity: Physical activity that does not cause sweating or hard breathing

Morbidity: Any departure, subjective or objective, from a state of physiological or psychological well being. In this sense, sickness, illness, and morbid condition are similarly defined and synonymous.

Mortality rate: A rate expressing the proportion of a population who die of a disease, or of all causes. The numerator is the number of persons dying; the denominator is the total population (usually the midyear population) in which the deaths occurred. The unit of time is usually a calendar year. To produce a rate that is a manageable whole number, the fraction is usually multiplied by 1,000 to produce a rate per 1,000. This rate is also called the Acrude death rate.@

Obesity: A condition in which a person has abnormally high amounts of unhealthy body fat; medically defined as a BMI of 30 or greater.

Overweight: Being too heavy for one's height. Excess body weight can come from fat, muscle, bone and/or water retention. Being overweight does not always mean being obese (25.0 to 29.9 BMI).

Palliative care: Care that does not alter the course of a disease, but improves the quality of life.

Prevalence: In medical terminology, prevalence typically has been defined as the number of cases of a disease that are present in a population at a point in time. In the case of smoking prevalence in population, the term in used to define the number of people in that population who are regular smokers.

Practice guidelines: Provide physicians and other healthcare providers with a medically proven set of directions or principles to assist with patient care decisions, appropriate diagnostic, therapeutic or clinical procedures; incorporating the best scientific evidence with expert opinion. Recommendations are based on rigorous clinical research and professional consensus.

Primary prevention: The reduction or control of factors believed to be causative for a health problem and includes reducing risk, education to reduce sexually transmitted diseases, and environmental exposures such as reducing ambient lead to prevent intellectual impairment. This category also includes health-service interventions, such as vaccinations or such preventive Atherapy@ tools as fluoridated water supplies or dental sealants.

Prostate-specific antigen: A protein whose level in the blood goes up in some men who have prostate cancer or benign prostatic hyperplasia. Also called PSA.

Quality of life: In cancer treatment, the concept of ensuring that cancer patients are able to lead the most comfortable and productive lives possible during and after treatment. New treatment techniques and social and emotional support groups are adding to the quality of life for cancer patients as well as to their survival.

Radon: A radioactive gas released by uranium, a substance found in soil and rock. Exposure can damage lung cells and lead to lung cancer.

Regional: Cancer that extends beyond the limits of the site of origin into surrounding organs or tissues or regional lymph nodes.

Risk factor: Anything that has been identified as increasing the chance of getting a disease, e.g., tobacco use, obesity, age, or family history of some cancers.

Secondary prevention: Involves early detection and treatment, such as mammography for detecting breast cancer or Pap tests for detecting cervical cancer.

Secondhand smoke: Smoke that comes from the burning end of a cigarette and smoke exhaled by smokers. Also called ETS or environmental tobacco smoke. Inhaling ETS is called involuntary or passive smoking.

Stage: A distinct phase in the course of a disease, in cancer, typically defined by containment or spread of the tumor: in situ, localized, regional or distant spread. Tertiary prevention: Involves providing appropriate supportive and rehabilitative services to minimize morbidity and maximize quality of life, such as rehabilitation from injuries. It includes preventing secondary complications.

Translational research: Provides a link between bench science and bedside clinical medicine.

Vigorous physical activity: Physical activity that causes sweating and hard breathing.

Member Information Form: To join the MTCCC in preventing and controlling cancer in Montana, please complete and return this form.

#### Name:

((Credentials):

(Work) Title (put N/A if not applicable):

(Work) Organization (put N/A if not applicable):

Mailing Address (street, city, state):

Zip:

Delivery Address (street, city, state -- if different from mailing address):

Zip:

Contact Phone:

First Telephone Number (please indicate whether this is your home, work or cell number and provide area code, number and your extension, if applicable):

Fax (area code and number):

Second Telephone Number (please indicate whether this is your home, work or cell number and provide area code, number and your extension, if applicable): :

E-Mail Address:

Organization or group that you officially represent (if applicable):

What is your area of interest? Please indicate which implementation groups you want to work on: Prevention Team; Early Detection Team; Treatment and Research Team; Quality of Life and Survivorship Team; Data Workgroup; Education Workgroup;

Funding and Resource Development Workgroup; Legislative Workgroup;

Communication Standing Committee; Evaluation Standing Committee; Evolution Standing Committee.

Are you 17 years of age or younger?
If you are, please provide the name of an adult sponsor:
Area code, telephone number and extension of adult sponsor:

Return this form to:
Sue Miller, DPHHS
1400 Broadway Room C-317 or P.O. Box 202951
Helena, MT 59620-2951 or e-mail sumiller@mt.gov or call 406-444-3624.

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